



SCHOOL OF  
HEALTH SCIENCES  
JÖNKÖPING UNIVERSITY

# CARE TRAJECTORIES IN THE OLDEST OLD

Marie Ernsth Bravell

SCHOOL OF HEALTH SCIENCES, JÖNKÖPING UNIVERSITY  
DISSERTATION SERIES NO. 3, 2007

From the Institute of Gerontology,  
School of Health Sciences, Jönköping University, Sweden

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# Abstract

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This thesis demonstrates relations among health, social network, ADL and patterns of care in the oldest old guided by a resource theoretical model.

The analyzed data are based on two studies: the Nona study, a longitudinal study of 157 individuals aged 86 to 94 years, and the H70 study, a longitudinal study of 964 individuals aged 70 at baseline. Data were collected by interviews and to some extent in the H70 study, medical exams and medical records.

The results demonstrate that perceived resources seem to affect patterns of care to a higher extent than the more objective resources in the sample of the oldest old. On the other hand, sociodemographic variables such as gender, marital status and SES, in addition to the more objective resources of having children nearby and the number of symptoms of illness predicted institutionalization during a subsequent 30-year period from the age of 70. The proportion of elderly persons' institutionalization was further significantly higher than that generally found in cross-sectional studies. ADL was one of the strongest predictors for both use of formal care and institutionalization in both samples, indicating an effective targeting of the formal care system in Sweden. The care at end of life in the oldest old is challenged by the problems with progressive declines in ADL and health, which makes it hard to fit in the dying oldest old in the palliative care system. There is a need to increase the knowledge and the possibility for care staff to support and encourage social network factors and for decision-making staff to consider factors beyond ADL.

Keywords: oldest-old, health, social network, ADL, care, institutionalization, end-of-life

## Original papers

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III. Ernsth Bravell M., Berg S., Malmberg B., Sundström G. Sooner or later in institutions in late life. Submitted.

IV. Ernsth Bravell M., Malmberg B., Berg S. End of life care in the oldest old. Palliative & Supportive Care. Accepted for publication.

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# **I. Introduction**

One of the most frequently used introductory phrases in gerontology research has to be; “the population of elderly persons is increasing...” which is used to imply the necessity for research about this population. Not only will the elderly population increase but among them the oldest old age group will increase most rapidly. This group of the oldest old will probably have the greatest need for service and care due to age-related diseases and impaired functional capacity (Agüero-Torres et al. 1995). They are also characterized by social risk factors (Kivett et al. 2000). This thesis will try to elucidate care trajectories in the oldest old by using a resource theoretical model introduced by Malmberg (1990). In this model different categories of actual and perceived resources are discussed in relation to demands of the surrounding environment. Understanding the role of perceived and actual resources of the oldest old may be especially important because the adjustment of an individual can be explained by the interplay between accesses to resources, actual and perceived, and the demands from the surrounding environment (Malmberg and Berg 2002). Health, social network, functional capacity and care patterns in the oldest old will thus be in focus for this dissertation, guided by a resource theoretical model.

In the introduction of the thesis, factors of relevance for care trajectories in the oldest old in view of the resource theoretical model will be discussed. At first, features of the oldest old and the resource theoretical model will be presented. According to the model individual and interpersonal resources will be discussed in terms of health and social network. Activities in Daily Life (ADL) will be discussed as an expression of when resources do not meet up to environmental demands, and finally different types of care are described.

## **I.1. The oldest old**

The definition of the oldest old has been increased from the age of 80 years or older to encompass only those individuals older than 85 years of age. This dissertation uses the term “the oldest old” to define the population of individuals over 85 years of age, but different terms will be used when describing other studies, depending on how the authors defined their sample. In Sweden, in the next fifteen years, the population of the younger elderly (65 – 79 years) will increase the most, followed by the population over 80 years of age (Andersen-Ranberg et al. 2005; Swedish

Association of Local Authorities and Regions 2007). This phenomenon has given rise to the suggested paradox about the increased number of centenarians: the progress in health and living conditions tends to increase the proportion of frail individuals in successive generations (Yashin et al. 2001).

The population of the oldest old poses a great challenge to the researcher because there are methodological challenges specific to measuring this age group, such as sampling errors and large non-response rate due to frailty, co-morbidities, cognitive problems, lack of response accuracy due to visual and hearing changes and slowed mobility and response times (Larsson and Thorslund 2006; Leahy et al. 2005; Rodgers and Herzog 1992). Yet, studies addressing the specific issues of these age groups are essential. Not only will this population increase but they are also a unique population in several ways. Firstly, it includes a much greater number of females than males, a fact that often affects the results in studies of the oldest old. Old age is also a risk factor for many diseases, which means that individuals in these older age groups are more likely to have higher levels of disability as well as extensive co-morbidities, even if the clinical conditions vary greatly (Jopp and Rott 2006; Larsson and Thorslund 2006; Motta et al. 2005; Suzman and Manton 1992). Advanced age is also one of the most important factors contributing to frailty, problems with ADL, dependency and level of received care (Allen et al. 2001; BURDIS 2004; Covinsky et al. 2003a; Hellström and Hallberg 2001; Iwarsson 2005; Klein et al. 2005; McGee et al. 1998; National Board of Health and Welfare 2000). Considering only the population of the oldest old, studies indicate that despite the increased risk of ADL problems and dependency, the oldest old individuals often perceive their health relatively positively (Andersen-Ranberg et al. 2005; Jopp and Rott 2006; Leinonen et al. 2001a; Schroll et al. 1996). Another important aspect concerning studies of the oldest old is that, regardless of the higher risk of disease and disablement, these individuals constitute a group of survivors and they contribute to gerontology knowledge. A Swedish study of centenarians (Samuelsson et al. 1997) found that after the age of 80 the incidence of severe disease was relatively low and that the diseases had occurred late in life. Furthermore, research has demonstrated that even if centenarians had chronic, invalidating diseases, they were still autonomous in managing their daily lives (Andersen-Ranberg et al. 2001; Motta et al. 2005) and despite substantial constraints in functioning, they felt happy (Jopp and Rott 2006) and just as satisfied with life as younger elderly individuals (Field and Gueldner 2001). Therefore, even if diseases and disability are highly correlated with old age, other factors are important when it comes to how the population of the oldest old manages their daily life. It is possible that social network and perception of health affect daily life for the oldest old more than objective health does, because they have adapted to their situation.

## 1.2. Theoretical background

This dissertation focuses on the relationships among health, social network, ADL, and patterns of care from a resource theoretical point of view. The current resource theoretical model was introduced by Malmberg (1990) and is of interest due to the categorization of resources separated into objective and subjective. The model is in many ways similar to other theories based on the concept of resources.

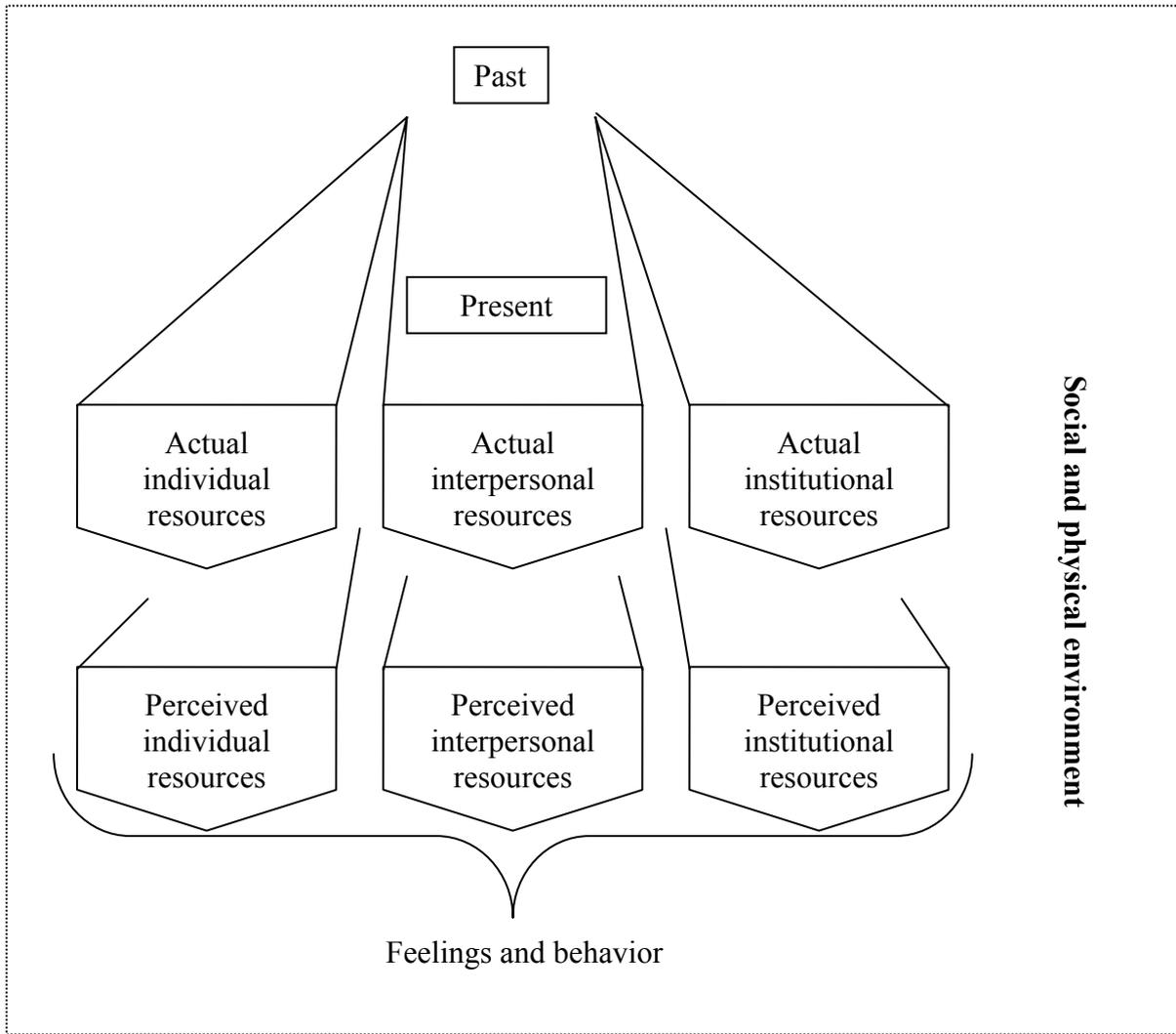
For example, in 1973 Lawton & Nahemow introduced the ecological model that predicts outcomes in terms of adaptive behavior and affect on how a person's competence interacts with the demands or press from the environment. The ecological equation is  $B = f(P, E)$ , that is, behavior is a function of the person and the environment. According to the model, an individual's *competence* includes biological health, sensory and perceptual capacities, motor skills, cognitive capacity and ego strength. *Environmental press* is defined in normative terms and a gross classification has been proposed where the environment is divided into five categories: *physical* (objective: what can be counted, and subjective: personally described, for example housing deficits, ecological characteristics and so on); *personal* (one-to-one relationships: friends, family, and support networks); *suprapersonal* (modal characteristics of people in geographic proximity of the subject as in social area analysis); *social* (organizational character, social norms, cultural values, legal systems, etc.); and *small group* (the dynamics that determine the mutual relationships among people in a small group in which all members have some one-to-one interaction). The outcome of the ecological model is behavior, which could be an outwardly observable motor response or an inner affective response. Behavior and affect must be thought of as variables that change over time, because press from the environment and competence of the individual is fluid, and can change over time and across different intra-individual domains (Lawton 1982; 1999).

Hobfoll (1989) introduced a resource theoretical model, called conservation of resources (COR), which is based more on resources than on environment: the outcome is stress. The model identifies four kinds of resources whose loss and gain might result in stress or well-being. *Object resources* are defined or valued from their physical value or their acquired secondary status (for example a house or a car). *Conditions* are defined as resources to the extent that they are valued and sought after, such as marriage, tenure, and seniority. *Personal characteristics* are resources in that they generally aid stress resistance. *Energies* include resources such as time, money, and knowledge. Social support is not included in these resource categories and according to Hobfoll

(1989), social relations are resources that could provide or facilitate preservation of valued resources (conditions), but they could also detract from an individual's resources. According to COR, stress follows: 1) when individuals are threatened to lose resources, 2) when individuals actually lose resources, or, 3) when individuals invest resources without appreciable resource gain. In order to gain resources and prevent loss, the individual has to invest other resources. In conclusion, individuals rich in resources are less vulnerable to stressful events such as loss of a close friend or spouse, events that are more likely to occur in advanced age (Hobfoll 1989; 1991).

Foa & Foa developed a resource theory about the cognitive organization of interpersonal resources that is a development of earlier exchange theories. They define a resource as anything transacted in an interpersonal situation, that is, a resource is any item, concrete or symbolic, which can become the object of exchange among people. The resource theory by Foa & Foa classifies rewards and punishments transmitted in interpersonal encounters into six categories: love, status, information, money, goods, and services (Foa et al. 1993).

However, when studying elderly and oldest old individuals, it may be especially important to understand the different roles of perceived and actual resources (Malmberg and Berg 2002). Adjustment or adaptation of an individual can be explained by the interplay between access to resources and the demands from surrounding environment, as suggested by the described models. However, the resource theoretical model includes and divides actual and perceived resources and relates them to demands from the surrounding environment (Figure 1). The main idea is that more resources, actual or perceived, make it easier to meet demands from the surrounding environment. It is also assumed that actual resources are reflected to a certain extent in the perceived resources, but there is a possibility for some contra flow. Both actual and perceived resources are divided into three categories: individual, interpersonal and institutional resources. Individual resources are defined as any internal assets that an individual possesses, including physical and mental health, physical strength, intelligence and knowledge. Interpersonal resources are defined in terms of positions taken in the person's social network, spouse, children, other relatives, friends and acquaintances. Institutional resources are defined in terms position of power in society, such as social class, financial situation, work position and education.



*Figure 1. A tentative theoretical resource model.*

Perceived resources are affected to an extent by the actual; for example, if an elderly person suffers from a disease, they would probably perceive their health as worse than an elderly individual without any disease would. Perceived health can also (but to less degree) be affected by actual interpersonal and institutional resources, but the impact might be reversed. For example, if an elderly individual feels lonely, these feelings can negatively affect their perceived quality of social network and change the content of the actual interpersonal resources. The impact of actual and perceived resources together is reflected in feelings and behavior, in constant interplay with the surrounding environment. The basic assumption is that the richer the resources, the richer the possibilities of managing the social and physical environment. The perspective in Figure 1 moves from past to present, implying that the present is related to earlier situations. The surrounding

environment also changes over time and the relationship between actual and perceived resources and expressed feelings and behavior have a history in a changing environment (Malmberg 1990).

The resource theoretical model will be used to guide this dissertation. However, it is not possible to focus on all elements of the model. This thesis focuses mainly on some aspects of actual and perceived individual and interpersonal resources and the outcome in terms of use of care and institutionalization, with ADL as an indicator of when resources fail to meet the demands of the environment. Thus, both actual and perceived health are considered individual resources, and social networks are defined in terms of contacts (as in objective) and feelings of contacts (as in subjective), considering children, other relatives and friends as interpersonal resources. The effect of marital status was considered singly, striving to assess its specific effect on patterns of care. Therefore it is not included in the social network indices. Institutional resources receive comparatively less attention in this dissertation, and in the single study in which socioeconomic situation (SES) is used, it is defined as a sociodemographic variable.

### **1.3. Individual resources as in health**

It is well recognized that health is a complicated concept that includes biological, psychological and social factors. Among elderly individuals, health encompasses far more than the number of diseases or symptoms but it is also related to life satisfaction, functional ability and social network factors. Abu-Bader et al. (2002) demonstrated that physical health, emotional balance and social support are highly correlated with life satisfaction in an elderly sample. A number of studies have reported correlations between measures of health and ADL (i.e. Bardage et al. 2005; Bryant et al. 2000; Chen and Wilmoth 2004; Hellström et al. 2004) and received care but the relationship between these measures has shown to be very complex (Kempen et al. 1996; Leinonen et al. 1999; Manderbacka and Lundberg 1996; Partakki et al. 1998). Because health is a complex concept, there have been many different suggestions about the best way to measure it. Parker and Thorslund (2007) raised the question: “How should researchers best measure the health of the elderly population to reflect need for care?”. In their review, they highlighted global self-rated health, self-reported health items, functional impairment, disability and test of function. This issue is of immediate interest for this dissertation, which uses self-rated health, together with measures of social network, as indicators of perceived resources. Self-reported health items are used as indicators of objective individual resources, and self-reported functional disability (as in

ADL function) is used as an indicator of unbalance in resources and demands. Use of care is considered as the outcome.

### **1.3.1. Subjective health**

It is important to separate the individual's subjective feelings about their health from the more objective health status, because they capture different dimensions of the individual's health status. There are often strong relationships between objective health measures and self-rated health and perceived health. Self-rated health have recently been topics of interest in gerontology research, not only because it is an easily measured concept in the social sciences (George 2001), but also because self-rated health has been shown to be related to quality of life (McCamish-Svensson et al. 1999; Schroll et al. 2002), social support/social contacts/relations (DuPertuis et al. 2001; Hyduk 1996; Lund et al. 2004) and ADL or disability (Leinonen et al. 2001b), and also serves as a predictor of survival in elderly populations (e.g. Berg 1996; Idler and Benyamini 1997; Marcellini et al. 2002; Pedersen et al. 1999) even when effect of physical health, chronic illnesses and functional status are considered (George 2001).

In a review of studies concerning self-rated health and mortality, Idler and Benyamini (1997) found that that one question is often used to estimate perceived overall health: "How in general would you estimate your health?". Some authors added phrases such as "... in relation to other in your age?" or "... at the present time?" which add another dimension to the estimation. They concluded that the effect from the one simple question of perceived health was the most powerful self-assessment on mortality (Idler and Benyamini 1997). However, Andersen et al. (2007) found different results when comparing global self-rated health and comparative self-rated health that should be considered when interpreting results on self-rated health. Even so, the global self-rated item seems to be the most common, and it is related to more than just mortality. For example, McCamish-Svensson et al. (1999) demonstrated that in a sample of old-old individuals, self-rated health correlated more strongly to life satisfaction than did doctor-rated health.

Researchers have also sought predictors of perceived health. Leinonen et al. (1999) concluded that the concept of self-rated health among older people is multidimensional, and includes cognitive and sensory-motor performance and health behaviors. The most powerful predictors of self-rated health were performing ADL and number of chronic diseases, but the models for men and women differed. Women with lower numbers of depressive symptoms and men with better cognitive capacity rated their health better. Bryant et al. (2000) demonstrated that number of

chronic diseases, worsening of reported diseases/conditions over a 12-month period, dependency in ADL, physical performance and mobility, changes in diseases, ADL and mobility and the use of medical care, contributed most to the variance in perceived health in elderly individuals. Education was a small but significant contributor. Chipperfield et al. (2004) demonstrated that perceived control and stability of it affected perceived health significantly.

Most descriptive data demonstrates that elderly persons in Europe consider themselves to have a good health (e.g. Leinonen et al. 2001a; Schroll et al. 1996) and also that stability in self rated health is more common than change (Leinonen et al. 2002). It also seems that self-reported health is stable in advanced ages, several studies demonstrate that even the oldest old rate their health as good, sometimes even better than the younger old do (Denning et al. 1998; Kivett et al. 2000; Nyqvist et al. 2006). Even so, Andersen et al. (2007) could demonstrate longitudinal declines of both global and comparative self-rated health in a study of Danes 45 to 102 years of age. Studies from Sweden are still positive. In the year 2000, 86% of the elderly 75 years of age and older estimated their health to be good or pretty good, and among the oldest old (over 85 years old) the proportion that considered themselves to have good or pretty good health was 84% (National Board of Health and Welfare 2000).

Several studies also show a tendency to improved health among the elderly population such as National Board of Health and Welfare (2000; 2005a) and Larsson and Thorslund (2006) but a decade later the Sweold-study demonstrated a decline in self-rated health among the elderly (Thorslund et al. 2004). Not only is there contradictory results in the age effects of self-rated health, but Larsson and Thorslund (2006) also found that health developments in Swedens elderly population appear to give different results depending on which years are compared, as demonstrated. There is also evidence of gender differences even they are inconsistent across studies. As Larsson and Thorslund (2006) showed: in a survey from 1990s women more often reported poorer health, however, that was not the case in the surveys from 1980s. Most studies, though, demonstrate that men rate their health as better (George 2001).

### **1.3.2. Objective health**

The more objective dimension of health is not as easy to capture as perceived health. As Larsson and Thorslund (2006) discussed the border between normal ageing and disease is fluid and it is difficult to define the line. Objective health has been measured in several different ways in research on elderly individuals and there is no “golden way” to measure this as with “global self-

rated health". There seems to be a problem identifying the best way to capture objective health. Some of the difficulty might be because researchers do not agree on the purpose for measuring objective health. For example, there has been a debate around a measure of objective health called "the SENIEUR protocol" (Castle et al. 2001; Ershler 2001; Ligthart 1984; Ligthart 2001; Miller 2001; Pawelec et al. 2001) where the discussion concerns distinguishing between "normal aging" and disease in older individuals.

Many studies use self-reported health indicators as alternatives to the SENIEUR protocol or other methods using medical exams and medical records. The most common method is to ask the respondents about health problems such as diseases and symptoms. Braungart (2005) used and categorized the participants, based on their responses to a list of 40 diseases and symptoms, into three groups: presence of 1) very life-threatening; 2) somewhat life-threatening; or 3) non life-threatening diseases, a classification originally proposed by Gold et al. (2002). This way of examining objective health did not turn out to be related to ADL capacity, as expected. As Parker and Thorslund (2007) indicate, questioning elderly individuals about symptoms and diseases has some disadvantages, such as the necessity for the respondents to remember all of their symptoms and diseases, which could be difficult for the oldest old and those with declining cognitive function. One must also distinguish between reported diseases and reported symptoms, where symptoms are more subjective than disease and may reflect underlying causes other than that indicated by the somatic manifestation (op.cit).

If we for now consider the number of diseases and symptoms as indicator of objective health, several studies has demonstrated increases of diseases and symptoms in the elderly population in the past years. Parker et al. (2005) found an increase in a number of symptoms and diseases in very old people between 1992 and 2002 , similar to Rosén and Haglund (2005) and Larsson and Thorslund (2006) who demonstrated increases in the prevalence of long-standing diseases among elderly between 1988/89 and 2002/03. Further, Schroll et al. (1996) showed that even if there was no increase in the number of elderly participants reporting chronic diseases, the number of chronic diseases per participant significantly increased between 1988/89 and 1993.

Studies have also demonstrated increases of diseases and symptoms with advancing age as well as gender differences. Elderly women tend to report more diseases than elderly men and also the increase of several diseases and symptoms is more dramatic in women (Denning et al. 1998; Thorslund and Lundberg 1994; von Strauss et al. 2003). Many of those diseases, and the drugs used to treat them, affect the performance of ADL in the elderly (Hogan 2000). On the other

hand, Andersen-Ranberg et al. (2001) found that centenarians could not be considered healthy according to diseases and chronic conditions, but they could be considered as autonomous, a state that probably is more related to use of care and institutionalization. Similarly, others have found that even if the elderly and the oldest old report more diseases and symptoms, they manage to live independently (Parker et al. 2005; Spillman 2004; von Strauss et al. 2000). Therefore, the question is whether diseases and symptoms are reliable indicators to use for predicting use of care. As previously stated, there is no consensus about the golden way to measure objective health, but as Nyqvist et al. (2006) and Parker and Thorslund (2007) have concluded, it is important to use several different health measures besides perceived health to get a comprehensive picture of health status in the oldest old.

### **1.3.3. Relation between subjective and objective health**

Studies of the oldest old show that self-assessments of health bear only a limited relationship to physical conditions, or to the ability to perform various tasks (Bury and Holme 1991). Malmberg and Berg (2002) suggested that objective health is reflected in the subjective ratings, and some studies show a correlation between the two. McCamish-Svensson et al. (1999) found a significant correlation between self-rated health and doctor-rated health, even if self-rated health was more strongly related to life-satisfaction. Bardage et al. (2005) also found that medical indicators of health (such as reported diseases) were related to self-rated health. On the other hand, Schroll et al. (1996) found it striking that so many elderly individuals reported chronic diseases and impairments, yet still estimated their health as good. However, these results have been confirmed in a number of studies. Chipperfield (1993) found that over half of the elderly in her study rated their health more favourably than was expected from the objective measures of health. It was uncommon for the elderly to underestimate their health, only a very small proportion rated their health as less favourable than their actual health status. Several other studies have demonstrated similar results: that even if elderly individuals, even the oldest old, have a high prevalence of reported physical problems, they often rate their health as good (Dening et al. 1998; Kivett et al. 2000; von Heideken Wågert et al. 2006). Parker and Thorslund (2007) concluded that studies of the elderly often demonstrate increases in reported diseases and symptoms over time, but that self-rated health tends to improve with advancing age.

Kempen et al. (1996) tried to find differences between perceived health and domain-specific estimations (including affective functioning, behavioral dysfunctioning, somatic symptoms and chronic medical morbidity), and found that the difference in positively perceived health was

badly reflected by the domain-specific estimation. On the other hand, negatively perceived health was well reflected by the domain specific estimation. In total, 42% of the variance in perceived health could be explained by the domain-specific estimation and all *beta* coefficients were significant but somatic symptoms. Borawski et al. (1996) used open-ended responses regarding attributes underlying health appraisals, with five categories as outcome: physical health, attitudinal/behavioral, externally focused, health transcendence, non-reflective. What was interesting was that the older the respondent, the less likely they were to focus on physical health. Therefore, as the resource theoretical model (Malmberg 1990) indicates, objective individual resources (health) are reflected to a certain extent in the perceived resources, but there is also an impact from other sources, for example interpersonal resources. This might be even truer for the oldest old, considering the results of Borawski et al. (1996).

#### **1.4. Interpersonal resources as in social network**

The relationships between social network, health, function in daily life and mortality are of major interest in gerontology research, and social support has been demonstrated as a key determinant of successful ageing. Nevertheless, the research about social support of the elderly is complicated and there are several different ways to measure it (Krause 2001). Due et al. (1999) introduced a conceptual framework with social relations as the main concept, and used it to describe social relations in the Danish population. They divided social relations into “structure” and “function” where the structure of the social relations was defined as: *the individuals with whom one has an interpersonal relationship and the linkage between these individuals*. They suggest that the structure has two dimensions: formal relations and informal relations (i.e. social network). They defined function of social relations as: *the interpersonal interactions within the structure of the social relations*. Function covers the qualitative and behavioural aspects of the social relations. They also refer to Cohen and Syme (1985, see Due et al. 1999) who define social support as the resources provided by other persons. Their definitions and use of structure (measured by marital status, household composition, number of children, and frequency of contact with children, peers, friends, and others) and function (measured by emotional support/confidants and instrumental support/friends) (Due et al. 1999) are similar to how actual (structure) and perceived (function) social network are defined and used in this dissertation. Social contacts were considered as the more objective way to evaluate interpersonal resources and feelings of having friends and confidants were considered as subjective. The exception is the H70 study in which satisfaction

with children contacts and feelings of loneliness were used to measure the perception of interpersonal resources.

#### **1.4.1. Objective social network**

When discussing social network, the distinction between objective and subjective measures is not overtly obvious. The objective resources of social network probably affect the subjective feeling of social support, but a number of other factors, including perceived health, affect the social network as well. Age is a demographic factor shown to be related to social network, often in combination with other factors such as health or functional ability. Bertera (2003) demonstrated that age was negatively related to both social network contacts and telephone contacts and that health had a great impact on telephone contact and a small affect on other types of contacts. Poor perceived health and difficulties in performing ADL and physical activity were positively related to social contacts; therefore, in addition to advanced age, functional ability seems to affect social contacts. Hydyk (1996) concluded that old and very disabled individuals get a lot of social contact when their disability increases, but their social support decreases. As well, individuals with decreased perceived health showed low social support. Further, Bondevik et al. (1998) demonstrated that elderly individuals who needed assistance to perform certain ADL activities, such as continence, toilet visiting, and movement, showed a lower degree of loneliness, and concluded that ADL dependency is not necessarily equal to loneliness, either emotional or social.

On the other hand, Litwin et al. (2003) showed that individuals with a moderate or high degree of disability had a higher probability of having a limited social network. Avlund et al. (2002a) also demonstrated that poor functional ability predicted sustained low contact frequency and diversity in elderly individuals in the Nordic countries, as did Lund et al. (2004). Mendes de Leon et al. (1999) demonstrated that social network variables were generally positively related to both emotional and instrumental social support (having children and a confidant showed the strongest correlation), and that the total social network variable was significantly associated with a reduced risk of becoming disabled, as well as an increased chance of recovering from disability. Avlund et al. (2004a) found evidence to support the result that social relations provide some kind of protective effect against disability. They found a beneficial effect of having weekly telephone contact and suggest some possible explanations: 1) face-to-face contact means that the family members perform tasks instead of encouraging the elderly individual to do the activities, or 2) face-to-face contact is an early indicator of difficulty performing activities. They also suggest that the telephone contact cause less strain and includes more positive informational support.

Thus, it seems to be disagreement in research on how social network are related to disability or health. Does higher dependency cause an increase in social contacts due to an increase in informal care provided, or do the functional limitations decrease the ability to meet with friends and relatives? Lund et al. (2004) proposed that deterioration in health reduces some social contacts and stimulate others, which appear to be a most likely conclusion.

Nevertheless, age seems to have some impact on social network factors, regardless of health problems and disability. Due et al. (1999) found remarkable age differences in both the structure and the function of the social relation when comparing groups of 25-year olds, 50-years olds, 60-years olds, and 70-year olds, where the older age groups had fewer social contacts than the younger age groups did. Kivett et al. (2000) also found significant longitudinal declines in social interaction among the very old, in both group participation and in visits with friends and neighbors. It is safe to assume that ones friends tend to pass away as people age and it may not be uncomplicated to find new friends. On the other hand, descriptive studies have demonstrated that most elderly individuals have stable social contacts. In Sweden for example, most elderly have contact with both friends and relatives (McCamish-Svensson et al. 1999) and they are not isolated even if increasing illness tends to result in fewer contacts (Lennartsson 1999), which is similar to international results (Cavallero et al. 2007; Cavalli et al. 2007). Avlund et al. (2002a) similarly demonstrated that many elderly people kept their social relations over time, as did Cavalli et al. (2007) even if they also found a decline in the very old individuals' level of social activities.

McCamish-Svensson et al. (1999) found interestingly that elderly individuals reported fewer friends with increasing age, but more frequent personal contact with them. Field and Gueldner (2001) came to the similar conclusion that almost all old individuals had lost friends to death, for example, but they were able to find new friends. They also suggested that as long as the oldest old individual has one friend remaining, that friend could become a "multipurpose" friend, performing many of the functions that earlier were spread over a larger network, similar to McCamish-Svensson et al. (1999). Further, Field and Gueldner (2001) found that there was no significant change the oldest old individuals' amount of contacts with children.

#### **1.4.2. Subjective social network**

Perception of social network as it is defined in this thesis is not as highlighted in gerontological research as the more objective measures of social contacts and social support. Nevertheless, Due et

al. (1999) indicated that perceived social support was the most important concept in relation to health. Further, Kelley-Moore et al. (2006) found that subjective feelings of social integration, measured by feelings of having companions to call upon and satisfaction with social life, were strongly related to perception of disability, independent of actual functional status and existing health conditions. They also emphasized the important role of family and friends in subjective evaluations of disability, showing that negative changes in satisfaction with social network accelerated the process of considering oneself disabled. Anticipated support could be interpreted as a kind of perception of the social network. In studies, anticipated support is related to the stress process, and anticipated support may be a more effective coping resource than the assistance provided by the “actual social network”. As with social contacts, anticipated support is influenced by a number of factors (Krause 2001). Elderly individuals who have received much assistance in the past are more likely to believe that their social network will help in the future as well (Krause 1997). Jopp and Rott (2006) found that centenarians who were embedded in a social network had a more positive future outlook, and it is possible that those individuals felt more secure surrounded by people who provide support.

Shaw and Janevic (2004) demonstrated that there are different associations between emotional and instrumental support and functional ability: individuals who believe that support was available to them were less likely to have functional disability. The authors also concluded that expected emotional support was related to functional ability only because of its correlation with instrumental support and that instrumental support seemed to be directly related to functional ability (Shaw and Janevic 2004). As with health, most elderly are satisfied with their social life (Cavallero et al. 2007; Field and Gueldner 2001; McCamish-Svensson et al. 1999) and contacts with friends, despite the decrease in the size of the “actual” social network. That is, the level of satisfaction with contacts does not necessarily correlate with the number of contacts (Holmén and Furukawa 2002).

## **1.5. Activities in Daily Life (ADL)**

A number of studies have shown associations between disablement and advanced age, disease, and physical condition, from the disablement process point of view (Verbrugge and Jette 1994). Jette et al (1998) demonstrated that mobility was related to age and muscle strength but not gender, and that mobility was a significant predictor for disability. McGee et al. (1998) also suggested

that the loss of ability associated with increasing age appears to be related to age-related changes in muscle strength. Reviews and research on disablement have also found correlations between disability and disease (Hogan 2000), as well as between disability, impairment, and functional limitation (Brach and van Swearingen 2002; Fields et al. 1999). However, Hogan (2000) concluded that the link between disease and disability is often hard to prove because elderly individuals often suffer from many different diseases and dysfunctions. Nevertheless, Hogan's review demonstrated that the oldest old report more disability than the younger old do. The population of the oldest old is a very special population due to the higher risk of becoming disabled, sometimes secondary to age-related diseases and sometimes due to age-related changes.

Jette et al. (1998) suggested that human behavior includes a complex interaction between many physical, cognitive and physiological factors and that it is more than just the sum of physiological functions. Femia et al. (2001) came to a similar conclusion when testing the full model. In their study, disability seemed to be as much a function of an individual's psychosocial characteristic as the degree of functional limitation and impairment. For this thesis, a measure of ADL is used and thought of as an indicator of unbalance between resources and the demands from the environment. The measure of ADL is supposed to capture the dimension of demands from the surrounding environment to some extent, as demonstrated Iwarsson et al. (1998) and Iwarsson (2005).

### **1.5.1. Measuring ADL**

Measuring ADL presents many difficulties, including defining disability or ADL function and formulating questions that will effectively and accurately elucidate the phenomenon under study. Avlund (1997) demonstrated several important issues that researchers face when measuring disability or ADL function, including the variation in how to measure ADL. Most studies that measure disability focus on ADL function; that is, the ability to perform tasks in daily life activities. Personal ADL (PADL) include basic, easily measurable tasks, whereas instrumental ADL (IADL) include more outgoing and complex tasks. IADL includes measures of more outgoing and complex tasks and different studies use different measures. Determining how to measure IADL and how to pose questions that will effectively elucidate the information sought is complex, and different studies use different measures. IADL measures are dependent on gender, culture, housing conditions, and leisure time interests. When one asks an elderly individual whether they can perform a certain task, and the answer is negative, one cannot be certain of the reason why. Potential reasons could be lack of physical ability, lack of skills (for example

cooking), lack of interest (work in garden has never interested me), or due to the physical environment (the “supermarket” is too far away and there are no good communications) or gender roles. Avlund (1997) refers to Deeg (1993, see Avlund 1997), who found that 72% of those who reported to be dependent on help for IADL needed help due to health problems, and 28% of them (33% of men and 21% of women) needed help due to situational factors (mostly due to different gender roles). This issue was also raised by Larsson (2006) who suggested that one explanation for the increase in ADL ability between 1988/89 and 2002/03 could be that men in the later cohort were more familiar with household tasks that have customarily been carried out by women. There are also more technology and services today, such as microwaves and ready-cooked food in the markets.

Parker and Thorslund (2007) raised another issue concerning ADL measures, specifically the problems with variations in questions asked. Questions about difficulties in performing tasks versus questions about needing help to perform tasks might result in different prevalence rates. When interpreting results one must consider how the authors define disability or ADL function and how the questions were asked. In the description of results from various studies, the same definitions as the authors used for the concepts of disability and ADL functions are used.

It is also important to distinguish how function in ADL is measured, if it is self-reported or if the measures are performance-based. Kempen et al. (1996) demonstrated that the majority (38%) of the variance in self-reported ADL could be explained by performance-based estimations, and also that other factors, such as emotional function and personality, were influential. Symptoms of depression were significantly related to self-reported ADL function but not to the performance-tested ADL function. These results indicate that the correlation between self-reported and performance-based ADL is not strong. On the other hand, Avlund (1997) concluded that even though measures of functional limitations, based on observations and timed performances, have face validity and reduce the influences of cultural environment and cognitive functioning, they are time consuming and expensive. Furthermore, they do not include the more complex ADL and it is possible that the actual performance measures something other than the subjective assessment, as discussed by Kempen et al. (1996). For this thesis, two different ways of asking questions about ADL are used; none of them is performance-based.

### **1.5.2. Factors related to ADL**

Several studies have documented significant relationships between increasing age and ADL-function (e.g. Allen et al. 2001; Braungart 2005; BURDIS, 2004; Covinsky et al. 2003a; Hellström et al. 2001; Iwarsson 2005; McGee et al. 1998; Roe et al. 2001). von Strauss et al. (2003) demonstrated in an analysis of some population-based studies on ADL in the elderly, that every study but one showed that disability increased with age. Avlund et al. (2003a) found that one third of the elderly persons in their study sustained good functional ability over a five-year period and another one-third of the women had deteriorating functional ability, as did 13% of the men. On the other hand, Holstein et al. (2006) found that even though 51% remained stable, and 37% declined in functional status over four years, 13% improved. Romören and Blekesaune (2003) also found a small group of elderly individuals (3.2%) that improved their ADL functional status over time. Nevertheless, in the study by Holstein et al. (2006) there was a significant decline in functional status in the group of the oldest old. In the next four year follow-up, Holstein et al. (2007) demonstrated that older age was related to deterioration in functional ability and also that the decline in ability was more rapid as age advanced. Similarly, Romören and Blekesaune (2003) and Béland and Zunzunegui (1999) found that the trajectory of disability among the oldest old often take a serious course, particularly among women. Li (2005) found a rapid decline in ADL ability preceding death or institutionalization, suggesting that steep decreases may be a precursor for these events, rather than an effect of advancing age.

The age effect is not easy to distinguish from other factors related to ADL. For example, there are gender differences in ADL function (National Board of Health and Welfare, 2005). Most studies conclude that females have higher risks of becoming disabled (Ahacic et al. 2003; Romören and Blekesaune 2003; von Strauss et al. 2003). However, Hellström et al. (2001) found that men reported more need for help with I-ADL and with dressing, and Holstein et al. (2006) found no gender differences in functional change over four years. Even so, most studies demonstrate that females tend to report more ADL problems and more disability (e.g. Avlund et al. 2003b; McGee et al. 1998; Puts et al. 2005; Schroll et al. 1996; von Strauss et al. 2003.) Reynolds and Silverstein (2003) found that age and being female were the only sociodemographic factors that predicted ADL problems in addition to several diseases, physical problems and behavioral factors. The trajectory of ADL function is complex, and age and gender seem to play important roles.

One of the issues in research has been to find factors related to ADL and functional ability other than age and gender. Avlund et al. (2002b) found that even though a large proportion of the

elderly had sustained good functional ability (from age 75 to 80 years), approximately one-fifth deteriorated, and for women, living alone was a risk factor for sustained need of help. Another study by Avlund et al. (2004b) found interesting gender differences in functional decline, namely that housing tenure was predictive for functional decline and mortality in men, while income was predictive for women. In yet another study, Avlund et al. (2003b) found that both men and women who felt tired in daily activities had a larger risk of becoming disabled. However, there were gender differences in the other factors that were related to onset of disability. For men, low social participation, poor psychological function, and physical inactivity were risk factors of onset of mobility disability; for women, the risk factors were receiving home help, low sense of coherence and, physical inactivity. Further, McGee (1998) found that except for increasing age and being female, risk factors for decreasing or lost ability in ADL were to live somewhere other than home (i.e. institutionalization), to have low eyesight and speech problems, to belong to a lower social class and to have lower education. Perceived health had large affect on ADL ability when it was added into the model. Béland and Zunzunegui (1999) demonstrated that, besides gender and age, less education, being a manual worker, having low income, and having many chronic diseases and depressive symptoms affected decline in ADL function. Roe et al. (2001) found that the elderly believed that underlying diseases affected their ADL ability and the help they needed, but so did the surrounding environment in some cases, similar to results reported by Iwarson et al. (1998). Taylor and Lynch (2004) demonstrated that the trajectory of disability was strongly related to social support and depressive symptoms in later life. Therefore, a number of factors others than disease, age and gender have some impact the ADL function, reinforcing the fact that the trajectory towards disability is multifaceted.

### **1.5.3. ADL in the elderly population**

Statistics from the National Board of Health and Welfare (2005a) showed that in Sweden, 14% of elderly individuals 65 to 79 years of age and 54% of those over 80 years of age had some type of ADL problem that required help. Further, they demonstrated that the proportion of elderly with ADL problems in need of help decreased between 1988/89 and 2002/03, in both the “younger” and “older” age groups. The authors suggested that the decrease in ADL problems was due to a combination of increased functional capacity of the elderly population and changes in the elderly individuals’ surrounding environment, owing to more modern facilities and technical assistance. Several other authors have proposed the explanation as well. Iwarsson et al. (1998) for example, found that most of the elderly in her study were relatively high functioning but also that physical environmental actions, such as housing adaptations used as compensatory strategies have

had their intended effects. Another Swedish study (SWEOLD) measured ADL and IADL disability between 1992 and 2002, and found no significant change in ADL or IADL with exception of a small increase in mild IADL impairments (Parker et al. 2005). The authors suggested that the subjective nature of the ADL measure could explain some of the lack of change, but so could an effect of environmental change and changes in expectations. Larsson and Thorslund (2006) and Larsson (2006) further discussed that the improvements in ADL found in their studies might reflect improvements in the individuals' health as well as changes in their surroundings. In the past few decades, there have been improvements in assistive technology, home modifications and other compensations for poor health. In Sweden, provision of assistive technology is based solely on need and is not dependent on age, economic status, or place of residence. However, information about what kinds of services are available and how to obtain them are crucial (Lilja et al. 2003) because these are important factors for independent management of ADL. For example, Allen et al. (2001) found that use of canes and crutches reduced both formal and informal hours of care, but there were also signs of substitution on ADL tasks.

## **1.6. Care patterns in the elderly population**

One issue discussed in gerontology research concerning the oldest old is whether they will have increased needs and how this would affect the care system for the elderly. Thorslund (1991) proposed five consequences already in 1991, that would result from an increased need for social services and care: families will have to contribute more; cooperation between families and the formal care services will have to increase; it will be necessary to make tougher decisions about priority; the private sector will expand; and, the younger elderly will be more involved in various ways. These issues are still of immediate interest and some of them will be discussed in this thesis.

### **1.6.1. Care for elderly living in the community**

von Strauss et al. (2000) discussed the fact that even if there is a decline in disability among the oldest old, the proportion of those individuals will increase and the decline will not affect the absolute numbers of disabled older people. This argument was confirmed by statistics from Sweden. The National Board of Health and Welfare (2005a) demonstrated a decrease in the *proportion* of elderly receiving Home Help services, and that the informal care has increased

between the years of 1988/89 and 2002/03. Recent statistics (year 2005) over use of formal care in Sweden showed that almost 135,000 older persons, living in the community, were granted home-help services and that the *number* of older persons with home-help services increased by 12% compared to the year of 2000. The increase was found in the population of persons aged 80 whereas in the age group 65 - 79 year there was a slight decrease in receiving such services. This indicates that approximately 3% of the 65 - 79 year-old age group and roughly 20% of those 80 years and older had home-help services (National Board of Health and Welfare 2006a).

However, capturing the use of informal care is not uncomplicated. As in the question concerning ADL problems, the meaning of informal care or assistance is different for different persons. Some may not consider a wife helping a husband to cook and clean as giving informal care, but would define a son providing the same assistance to his mother as informal care. Studies in the area of formal and informal assistance among the elderly yield differing results. Hellström and Hallberg (2001) demonstrated that nearly 39% of their sample (75 years or older) in need of assistance, received informal and formal help, 45% had only informal help, and 14% had only formal help. Women had home-help service more often than men did, wives helped husbands more than husbands helped wives, and children helped parents more in the oldest age groups as compared to the younger age groups. The National Board of Health and Welfare (2005a) showed that among women aged 80 and older and who lived alone, the proportion of home-help services decreased but the informal assistance increased. The pattern was not significant for men. Among cohabitating women (80 years of age and older), the proportion who received help from their husbands increased. Between the years 1988/89 and 2002/03, the proportion of elderly (65 years and older) that received home help declined, and the gap was filled by informal care. The overlap between family and state care was somewhat greater in 2002/2003. The decrease in received formal home help could not be explained by an increase in ADL functions among the elderly (Larsson 2006; Sundström et al. 2006). Johansson et al. (2003) also demonstrated that, except for informal care provided by spouses, the shrinking use of services in latter years has been outweighed by an increase in family-provided care and offspring assistance, where daughters were more frequent helpers than sons were. In the year 2000, women were nearly three times likely than men to be care providers for elderly individuals living alone.

It could be that elder care in Sweden is somewhat different than in other countries. In Sweden, the use of formal care is highly correlated with ADL (e.g. Davey et al. 2006; 2007; Hellström et al. 2004; Larsson et al. 2004; National Board of Health and Welfare 2006a) suggesting an effective targeting of supports based on needs. Davey et al. (2005) made a cross-national

comparison and found that, in Sweden, when elderly person suffer from ADL problems they get help from formal services and the informal services are complementary whereas in the United States the situation is reversed. Further, Davey et al. (1999) demonstrated that in United States, women were more likely than men to receive informal care, in Sweden the opposite was true. In United States, women tended to get help from daughters whereas women in Sweden tend to receive formal care, although Johansson et al. (2003) demonstrated an increase in assistance from daughters. A Danish study (Avlund et al. 2004a) found that the formal help as it was provided in Denmark, did not replace a lack of social relations. That is, if the elderly individual were unable to deal with daily activities the home helper took over.

### **1.6.2. Factors related to use of care in the community**

ADL problems is one of the most important factors influencing care patterns and institutionalization, and not only in Sweden (Davey et al. 2005; 2006; 2007; Hellström et al. 2004; Larsson et al. 2004; National Board of Health and Welfare 2006a). Several international studies have demonstrated that ADL function is an important determinant of the use of care. Slivinske et al. (1998) showed that estimations of ADL, estimations of cognitive problems, and perceived cognitive problems were significantly related to the type of service used. Roe et al. (2001) found that when elderly individuals had problems with shopping or their finances, for example, they received informal care but, when they had trouble cleaning, changing bed linens, or preparing meals, they received help from home help services.

Studies have also demonstrated a relationship between advanced age and the use of care (Davey et al. 2007; Hellström and Hallberg 2001; Hellström et al. 2004; Larsson et al. 2004). Allen et al (2001) identified advanced age (the only sociodemographic variable), living arrangements (living alone or in elderly housing), mobility equipment used and number of ADL and IADL difficulties, as predictors that significantly affected hours of *formal care*. Several sociodemographic variables were related with *informal care* received, such as age, ethnicity, education, several the access variables (such as living arrangement) and Medicaid. Mobility equipment use also contributed significantly, as did illness severity, number of hospitalizations and number of ADL and IADL difficulties. Dening et al. (1998) demonstrated that receipt of services was related not only to poor self-rated health and more reported physical symptoms, but also to ageing. However, the elder care situation differs between countries and should be considered when interpreting

results from international studies. In a Swedish study, Hellström et al. (2004) found higher incidence of diseases and symptoms among the elderly who received care.

Another factor, that has often been associated with use of care and institutionalization, is social support networks (Larsson et al. 2004; Samuelsson et al. 1988; Slivinske et al. 1998) and the possibility of receiving informal care (Houtven et al. 2004; Mack et al. 1997). Davey et al. (2007) found for example that living alone was associated with a lower likelihood of receiving informal support alone and a higher probability of receiving formal support alone. Similarly, Davey et al. (1999) found that childless individuals living alone were least likely to receive informal assistance. Larsson and Silverstein (2004) reported similar results, that those who were parents had higher odds of receiving informal support. They concluded that even in a welfare state such as Sweden, children are social assets in old age, because formal home-help services did not fully buffer the lack of care among childless individuals.

### **1.6.3. Institutionalization**

This dissertation uses data from the H70 study, which began before the ÄDEL-reform in 1992. The ÄDEL-reform was a comprehensive reform of the elder care system in Sweden. One of its features was that the responsibility for long term care of the elderly in institutions was transferred from the county council to the municipalities. This reform has had a large impact on elder care, institutionalization and care in terminal stages of life. The definition of an elder care institution varies based on geography, and different names are used, such as nursing home, old-age home and sheltered living. In this thesis, the term “institution” includes long-term geriatric care, nursing homes, old age homes or similar institutions for people with dementia and illnesses, and residential homes for people who cannot live in ordinary housing. Since 1992 in Sweden, all of these types of institutions have been called “special housing for the elderly”, and are strongly subsidized and usually run by the municipalities.

Elder care in Sweden, as in many industrialized countries, is a current target of discussion, specifically regarding the question about institutionalization versus the “stay in place-policy”. Today, about 2% of persons 65 - 79 years of age, and 17% of persons 80 years and older live in some type of institution. Between the years of 2000 and 2005, the number of institutionalized elderly decreased by about 15%. Most of the institutionalized individuals were women (70%) and aged 80 or more (80%). The proportion of the population aged 65 years of age and older who

were institutionalized decreased from 8 to 6% and from 20% to 17% for those aged 80 and older, as compared with the year 2000 (National Board of Health and Welfare 2006a). These numbers are cross-sectional and might be misleading because a far greater proportion of the elderly population will eventually move into an institution. However, the information available about this process is insufficient. When analyzing the prevalence of institutionalization among the elderly or analyzing differences between the institutionalized elderly and those residing in the community, cross-sectional analysis is the correct approach. However, the purpose of analyzing rates of institutionalization is often to investigate extent of the need for care in the elderly population. Kastenbaum and Candy (1973) raised this issue over three decades ago when attempting to analyze institutionalization in a different way: they analyzed the number of elderly individuals who died at some kind of institution. Lesnoff-Caravaglia (1978) performed another study in a similar way. Kastenbaum and Candy (1973) showed that the prevalence of institutionalization (at that time around 4%) differed from the percent of elderly persons who would end up dying at some kind of institution (20% in nursing homes and 24% in other types of institutions for the elderly). Lesnoff-Caravaglia (1978) reported similar results and concluded that the true extent of institutional care problems was greater than is usually assumed. Kemper and Murtaugh (1991) continued the argument for this issue nearly two decades later when they analyzed the cumulative risk or probability of nursing home placement. Their analysis suggested that 43% of those who turned 65 years old in 1990 would enter a nursing home before they die. Another decade later, one of the few attempts to analyze institutionalization in a similar way was made by Sundström et al. (2003) who followed a group of elderly from the age of 67 years to the age of 93 years, and found that 32% of them ended up and died in institutions.

Statistics indicate that since 1992, more than 50% of those who died at the age of 65 or older died in a place *other* than the hospital, compared to 25% before 1992. This can be attributed to the ÄDEL-reform, because before 1992, nursing homes were defined as hospital care but after 1992 nursing homes were defined as “special housings for elderly”. In recent years the number of elderly dying at the hospital has remained quite stable (National Board of Health and Welfare 2005b). Andersson et al. (2003) found that in ages 80 or more, about half (53%) of the respondents had lived in some kind of institution for more than one year before their death, and 21% of them had moved to an institution within a year before their death. One-quarter (26%) of the sample were still living in the community until their death and 45% were hospitalized at the time of their death (Andersson et al. 2003).

#### **I.6.4. Factors related to institutionalization**

The issues concerning who is institutionalized and why, may be more important than the precise measurements of rates. In 1988, Samuelsson et al. (1988) showed that the rate of final institutionalization had increased in the decades between 1938 and 1975. At the time of this study, persons who moved to nursing home (e.g. institutions) more frequently were women, had lower incomes, were more often from the working class, were more often childless and had less social contacts. Furthermore, the aged who eventually moved to a nursing home often suffered from chronic illnesses and were mentally impaired. Before they moved to the nursing home, half of them had received help and support from their families, and half had received public support (op.cit). In comparison to previous decades, the institutionalized elderly today seem to have more severe needs (National Board of Health and Welfare 2005b; Roe et al. 2001; Slivinske et al. 1998). Spillman (2004), on the other hand, demonstrated that even if there was a reduction in the disability rates between 1984 and 1999, the trend in the prevalence of institutional residence was relatively stable, at around 5% of the elderly population.

As indicated, ADL is one of the most important predictors of the use of formal care whether the care is provided in the community or in institutions (Allen et al. 2001; Larsson et al. 2004; Slivinske et al. 1998). Mack et al. (1997) reported that ADL assistance was mentioned only indirectly in comments on resources that respondents had about their social network. Environment and the identity they received from their homes were more important for their willingness and ability to stay at home. Therefore, the authors suggested that the municipalities that want the elderly to remain in their homes must find a way to estimate skills, resources, and needs beyond ADL.

In addition to ADL, there are a number of other factors that influence whether an individual moves to an institution or not. It has been suggested that the household composition and family network of the older person, especially with regard to cohabiting spouses or children offering help, may buffer against future institutionalization. Several studies indicate that marital status or living conditions (alone or not) is one of the most influential factors for institutionalization (Cribier and Kych 1999; Grando et al. 2002; Grundy and Jitlal 2007; Kemper and Murtaugh 1991; Larsson and Thorslund 2002; Slivinske et al. 1998; Sundström et al. 2003) where marriage seems to protect against institutionalization. Larsson and Silverstein (2004) also found that those who were parents had higher odds of receiving informal support and thereby avoiding institutionalization.

Moreover, Slivinske et al. (1998) found that respondents living in institutions were more likely to be widows/widowers, had lower economic resources and lower income, had lower levels of estimated and perceived social resources, had lower perceived function, and had a higher degree of religiosity, similar to the results from Samuelsson et al. (1988). One review by Hays (2002) showed that a key risk factor for institutionalization was household composition and that the most potent push factors included the death of spouse, abrupt changes in income or retirement and health events, such as hospitalization. Chen and Wilmoth (2004) found significant associations between subjective health, ADL and IADL limitations and moving to institutions among elderly. In the oldest old (mean age 90), nursing home use comparative to no services could be predicted by age, change in care pattern (from no use to use), decline in income, short time in the community, decline in interviewer-observed state of mind (which reflects how the interviewer perceived the respondents ability to follow and attend to the interview) and change in type of housing (Finlayson 2002). It is possible that informal care can act as a substitute for institutionalization and that old age, year of education, being wealthier and having at least one child with higher education affects the risk of nursing home use, as shown by Houtven et al. (2004).

#### **1.6.5. Care at end-of-life of the oldest old**

More than half of the population in Sweden dies when they are 80 years or older and 30% are between 65 and 79 years old (National Board of Health and Welfare 2006a). Nevertheless, research on the end of life care among the oldest old is relatively rare. Ahmed et al. (2004) and National Board of Health and Welfare (1997a; 2007) have published reviews about care at end-of-life in the old population that demonstrate a lack of research and publications, as well as a need to improve knowledge in the area of end-of-life care for elderly individuals. Other research (i.e. Andersson et al. 2003; National Board of Health of Health and Welfare 1997b; Teno et al. 2004) has demonstrated that there are unmet needs among elderly, dying individuals concerning information, emotional support, symptom relief and more. Most of the research about care at end-of-life for elderly focuses on special conditions such as cancer (i.e. Di Mauro et al. 2000; Sutton et al. 2003). Knowledge based on middle-aged or younger individuals, or specific diseases, may be of limited value for understanding end-of-life care among the oldest old, who predominantly experience chronic illness (Hallberg 2006) and prolonged periods of co-morbidity (National Board of Health and Welfare 2007). This means that the health of the oldest old usually deteriorates steadily or fluctuates during the last year (Rinell Hermansson 1990), and it is difficult to predict the duration of care (Wilkinson and Lynn 2001). Much of palliative care or

hospice care focuses on special conditions or diagnoses such as cancer and the population of the oldest old are probably difficult to accommodate within the palliative care model. Covinsky et al. (2003b) concluded that end-of-life care targeting individuals with problems clearly suggesting impending death (such as hospice care) is poorly suited to elderly dying persons with progressive frailty. The National Board of Health and Welfare (2006b) has demonstrated that most of the terminal care for individuals 80 years of age and older in Sweden is given in old-age institutions, similar to international trends (Grande et al. 1998; Teno et al. 2004; Wilkinson and Lynn 2001). The National Board of Health and Welfare (2006b; 2007) concluded that end-of-life care for the elderly is prolonged, and that the care has successively moved out of the hospitals to old-age institutions or to the community. Catt et al. (2005) found that when elderly were asked about where they would prefer to die, they preferred a hospital to home, but both young and old individuals preferred a hospice to home. However, elderly are less likely to be referred for palliative care (Ahmed et al. 2004; Grande et al. 1998; Kessler et al. 2005; Wilkinson and Lynn 2001) probably due to reasons discussed above. On the other hand, Hallberg (2006) concluded that palliative care may be appropriate for long-term care of very old people, but that care provided to older people at the very end of life needs adjustment. For example, end-of-life care for the oldest old should consider the importance of the social network as well as common fears about dying and being separated from one's beloved.

Whitaker (2004) found that the relatives of the elderly individuals living and dying at nursing homes were very important at end-of-life. The relatives contributed with many services, such as providing companionship for the elderly, understanding their health and needs, and communicating with the staff. They also shared the care and helped to prepare for death. Wilkinson and Lynn (2001) proposed that fear of death in advanced ages may reflect an exacerbation of anxieties concerning pain in dying or the subjective immediacy of death. Research (Ahmed et al. 2004; Hallberg 2006) has shown that there is a tendency to perceive the elderly as more accepting of death and less in need of support, but in fact, they have the same thoughts as any person at any age, and these need to be taken seriously. Ternstedt and Franklin (2006, see National Board of Health and Welfare 2007) also found that the elderly lacked opportunities to talk and to share their life experiences. In addition, (National Board of Health and Welfare 2007) concluded that it was not unusual for staff to have had limited knowledge about the elderly individuals thoughts and feelings before their death.

## 2. Aim of the thesis

The overall aim of this thesis is to investigate aspects of care patterns in oldest old individuals guided by a resource theoretical model. More specifically, the aims are:

- to describe the sample of the oldest old in the NONA study and to analyze associations among actual and perceived health and among actual and perceived social networks, guided by the resource theoretical model; also to analyze how the oldest olds' resources are related to ADL function, and patterns of formal and informal care.
- to investigate how health, social network, ADL, and use of care change over time in the NONA sample of the oldest old and to analyze how health and ADL affect survival.
- to analyze risk of institutionalization prospectively, cross-sectional and longitudinal in the H70 study from the age of 70.
- to describe the last year of life of a sample of the oldest old, focusing on care trajectories, health, social network and function in daily life activities.

In conclusion the aim is to give a description of the oldest old concerning individual and interpersonal resources and ADL, in relation to formal and informal care patterns, cross-sectionally and longitudinally.

## **3. Methods and samples**

### **3.1. Two different studies**

This dissertation uses two different studies: the NONA study (as in nonagenarians) and the H70 study (H as in health and 70 as in the age of the subjects at the start of the project). The general aim with the NONA study is to understand factors that contribute to independence at very advanced ages, and to be able to develop better ways to support independence and prevent disability. The aim is also to investigate the very old individuals' caregivers via the formal care- and social system to suggest better and more effective ways to organize care and support that will meet the elderly individuals' needs and also those of their relatives. The original aim of the H70 study was to make a survey of the social and medical conditions of the 70-year-old population in Gothenburg to obtain basic data for planning the care of the elderly and to contribute to knowledge of normal ageing. The subjects were also offered a thorough medical examination.

### **3.2. Ethical considerations**

In the NONA study the participants were given written and oral information about the study, stressing the confidentiality and the voluntary nature of participation and they were included if they gave oral consent to participate. The research ethics committee at Linköping University approved the study (Dnr: 99-078). The H70 study was approved by the Ethical committee at Göteborg University.

### **3.3. The NONA study**

#### **3.3.1. Sample**

Three of four analyses in this presentation use data from the NONA study, a longitudinal study of the oldest old living in the municipality of Jönköping, with the first data collection in the year 1999. Jönköping, a municipality in southern Sweden, has a population of about 120 thousand

inhabitants, approximately 17% of whom are 65 years and older. From the Swedish population register 300 people aged 86, 90 or 94 (100 from each age group) were identified and randomly selected and invited to participate in the study. From these 300 randomly selected elderly individuals 193 agreed to participate in the study, and from these 157 were by themselves able to provide information about their health, social network, ADL and patterns of received help. Another 36 participated through proxies but the data from the proxies interviews are not included in the two first studies. As one of the purposes was to investigate perceived resources the answers had to be based on the participants' own ratings. The first IPT (in-person testing) was performed in 1999, with two follow-ups, in 2001 and in 2003. After the death of the oldest old participants, an interview was performed with their relatives (n = 102), concerning the last year of life of the participant.

There were 46 men and 111 women (N = 157) who wanted and could participate on their own, which gives a participation rate of 56% excluding those that died before the first contact. Among the elderly participants, 55 lived in some kind of institution and 102 lived in the community in the first wave. The participants were fairly equally divided among the different age groups, with the youngest group including a few more and the oldest a few less (Table 1). For the first wave there was no significant difference between men and women in living arrangements but there was a difference between the three age-groups ( $\chi^2 = 6.73$ ,  $p < .05$ ). Those in the younger age group more frequently lived in the community and the oldest group more often lived in institutions. The sample is described in Table 1.

From 157 respondents who participated on their own at baseline, 98 persons could and wanted to participate in the second wave, at 2001. In the third wave at 2003, the respondents were reduced to 62. Three individuals participated in the first and third waves but not in the second.

**Table 1.** Description of the NONA sample

	1999 n = 157	2001 n = 98	2003 n = 62
<b>Gender</b>			
Men	46	27	19
Women	111	70	43
<b>Age</b>			
Born 1905	46	21	15
Born 1909	50	31	13
Born 1913	61	45	34
<b>Living arrangements</b>			
Community together	31	18	9
Community alone	71	45	24
Institution	55	35	29

### 3.3.2. Drop outs

In the first wave (1999), 18 persons from the 300 contacted died before the investigation started (12 persons aged 94, 4 persons aged 90 and 2 aged 86). Another 27 persons were not available, mostly due to hospital care, and 62 persons did not wish to participate for different reasons, more so in the youngest age-group. Further, 36 of the old individuals participated via proxies. This gives a participation rate of 56%, subtracting the deceased (68% if proxies are included). In the second wave 98 persons could and wanted to participate on their own while 17 participated via proxies. There were 38 of the 157 respondents who participated in the first wave, who were deceased at the second wave, and 4 respondents did not wish to continue. In the third wave 62 persons could and wanted to participate on their own, 19 participated via proxies, and 36 had died.

### **3.3.3. Proxy interview after death of the respondents**

The interview with the old individuals included a question about their closest relative, and if we were allowed to contact the relative for a telephone interview. In those 50 cases where proxies were used, they were asked if they were willing to participate in a later interview. Between 1999 and 2003, there were 109 respondents who died. Approximately one month after the time of death, relatives were contacted and invited to participate in a telephone interview about the family member's/relative's/friend's last year of life. One hundred and two proxies agreed to participate in the interview; most were relatives, primarily daughters (48) and sons (29), but also daughters-in-law (5), nieces and nephews (5), sisters (2), wives (2), sister-in-law (1), and cousin (1). Eight proxies were guardians, and one was a good friend. The interviews with proxies to the deceased respondents were performed parallel to the NONA study, from 1999 to 2003.

### **3.3.4. Procedures**

Interviews and in-person testing were performed in the old individual's own place of residence, both private homes and institutional settings. The interview contained questions about demographic information, medical history and health, ability to perform activities of daily living, social network, general psychological functioning and use of care, both formal and informal. In addition to the questions in the interview, several tests of physical functional ability and cognitive function were performed. The NONA study has a longitudinal design with three IPTs (in 1999, 2001 and 2003). The interview with proxies after death of the oldest old respondents was performed by telephone, approximately one month after the date of death. Information about death was collected from the Swedish population records. The interview was performed by the same trained registered nurses that did the main interview(s).

## **3.4. The H70 study**

### **3.4.1. Sample**

In 1971/72 a random sample of 1148 of all 70-year-olds living in the city of Gothenburg (which included about 30% of that population) was drawn from the population register of the city. From this sample, 973 (85%) participated in the study. There were follow-ups at ages 75, 79, 81, 82,

83, 85, 88, 90, 92, 95, 97, 99 and 100. After adjustments for internal missing data, the sample was reduced to 964 respondents at age 70, 537 at age 79 and 269 at age 85 (see Table 2).

### 3.4.2. Drop outs

Comparisons between participants and non-participants showed no significant differences as to sex, marital status, income or inpatient or outpatient psychiatric care but in somatic care: female non-responders had more hospital care during the preceding five-year period (Rinder et al. 1975).

**Table 2.** The H70 sample living in institutions or in the community at certain ages

	Age 70 N = 964		Age 79 N = 537		Age 85 N = 269	
	Men n = 448	Women n = 516	Men n = 209	Women n = 328	Men n = 86	Women n = 183
Community	438	506	188	298	65	135
Institutions	10	10	21	30	21	48

### 3.4.3. Procedure

The H70 study consists of two parts: a home interview and different clinical examinations at the outpatient clinic of a geriatric hospital. The home interview included questions about dwelling conditions, social network, social support, need for care, use of health care and use of medicines (Svanborg et al. 1977). The clinical part was comprised of different medical examinations and assessments of functional capacity. Information on whether a person died living in ordinary housing or had moved to an institution was mainly derived from the interviews, but as a complement the death certificates have also been used. Death certificates were obtained for all but 9 individuals and the four respondents who were alive at age 100 years.

### 3.5. Investigated variables for both studies

**Gender** was included as a sociodemographic variable in all four studies. However, for some of the regression analyses gender was excluded since it showed no correlation to the dependent variable.

**Age** was included as a sociodemographic variable in the studies based on the NONA sample, but not in the study based on H70 since the respondents were all 70 at the baseline, and accordingly increased their age the same way. It should be noted though when interpreting the NONA results that the variance in age only ranges from 86 – 94 years at baseline.

**Marital status** was included as a sociodemographic variable in all four studies. The reason for not including marital status as an interpersonal resource (social network factor) was that marital status has been demonstrated to have great impact on the outcome variables, patterns of care use and institutionalization (e.g. Cribier and Kych 1999; Kemper and Murtaugh 1991; Larsson and Thorslund 2002; Slivinske et al. 1998; Sundström et al. 2003). It was thus of interest to test the single effect of marital status. Marital status was categorized as: married (2), divorced/widowed (1) or never married (0).

**Socioeconomic situation (SES)** was included in the H70 study, but not in NONA. According to the resource theoretical model (Malmberg 1990) SES could be considered as an institutional resource. However, in the studies used there were no questions to catch the perception of institutional resources and even if it was possible to use the more objective dimension of SES as an institutional resource it could not be related to any perceived institutional resource category. Therefore SES was used as a sociodemographic variable in the third study on the H70 material and it was based on family income and the respondent's level of education. They were categorized as follows: Income, 1 = 0-7000 SEK/month (~1000 USD), 2 = 8000-17,000 SEK/month (~1140-2430 USD), and 3 = 18,000-121,000 SEK/month (~2570-17,290 USD). For education, 1 = none or incomplete primary school, 2 = complete primary school, and 3 = high school exam or higher. The scores for each variable were added, higher values indicating better SES. In the NONA material it was also difficult to get a fair picture of objective SES and therefore it is not included in those three studies at all.

**Objective health** was measured with similar questions in both samples. In NONA the more objective dimension of health was assessed using the following four variables: number of

diseases/symptoms, number of drugs, and whether the respondents had been in the hospital or consulted their general practitioner within the past two years. The items were dichotomized as follows: number of *reported diseases/symptoms*: two or more = 0, one or none = 1), *number of drugs used*: three or more = 0, none up to two = 1), *has visited hospital at any occasion in the past two years*: yes = 0, no = 1 and *has visited general practitioner at any occasion in the past two years*: yes = 0, no = 1. The dichotomous codes were combined into an objective health index ranging from 0 to 4.

In the H70 study the objective health measure was collected from both the medical examination and the in-person interview and included number of symptoms/diseases and the number of medications used. The actual number of symptoms/diseases and drugs were used in the analyses.

In the fourth study the proxies from the NONA study were asked to estimate the health of the oldest old individual one year, six months, and one month before their death (each coded as 3 = good, 2 = medium, and 1 = bad). They were also asked to describe the pattern of change in health.

**Subjective health** was measured by the items: “*perceived general health*”, “*perceived health compared to others*”, and “*if health problems prevented the respondents from doing the activities they wanted to do*” with three answer alternatives (0 = bad health, 1 = medium, 2 = good health) in the NONA study. The variables were added to a total perceived health score (0-6).

In the H70 study, perceived health was measured by asking individuals, “*Do you feel healthy?*” (no = 0, yes = 1).

**Social network** was measured in somewhat different ways. In NONA, indexes of objective and subjective social networks were used, but in the third study, with the H70-sample, single items were analyzed.

In NONA the **objective index of social network** included questions about *personal* and *telephone contacts with children*, and *personal contacts with relatives*. The answer alternatives ranged from 0 (no contact/no relative) to 6 (daily). The items were added together, forming a total objective social support score ranging from 0 – 18.

In the H70 study three questions were used to indicate the more **objective dimension of the social network**: *Does the respondent have children living nearby (in Gothenburg)?* (0 = no and 1 = yes), *How recently had the respondent met with his or her children?* (range from 0 = no children/no contact, 1 = met them over 1 year ago, to 7 = met them less than 2 days ago) *Does the respondent have daily contact with individuals other than their spouse or cohabitant* (0 = no, 1 = yes)?

The **subjective social network** index used in NONA included three variables: *feelings of having acquaintances* (range from 0 = not at all, to 3 = to great extent), *feelings of belonging to a circle of friends* (range from 0 = not at all, to 3 = to great extent) and *feelings of having confidants* (range from 1 = I have none, to 3 = I have two or more). The three items were added together forming a total score for perceived social networks ranging from 0 – 9.

In the H70 study, two items were used to assess the more subjective dimension of the social network: *Feelings of loneliness?* (0 = often feels lonely, 1 = sometimes feels lonely, and 2 = never or seldom feels lonely) and *Did they meet their children as often as they would like?* (0 = never have contact/no children, 1 = too often or too seldom, and 2 = satisfactory).

For the fourth study the proxies were asked about the old individuals' frequency of contact with children and relatives, similar to the in-person-interview with oldest old individual but with a less detailed answer alternative: *"How often did NN have personal contact with her/his children?"*, *"How often did NN have telephone contact with her/his children?"* and *"Did NN have contact with other relatives?"* and finally whether the children lived nearby.

**ADL function** was measured in different ways but it was always self-reported and not performance based. In study one and two of the NONA sample, the respondents were asked if they had any problems performing IADL tasks (cleaning their home, shopping, transportation, and cooking) and PADL tasks (bathing, dressing, using the toilet, getting in and out of bed, and eating). The alternative of answer was: (3 = no problems, 2 = small problems, 1 = great problems, 0 = cannot perform the task at all). For some analysis the answers were dichotomized into no/small problems (0) and great problems/cannot perform the task (1) and added together to indexes of PADL (range from 0 – 6)) and IADL (range from 0 – 4) or total ADL (range from 0 – 10) where higher values indicated more problems. For some analyses ADL was coded as: 0 = no ADL problem, 1 = only IADL problems, 2 = only PADL problem, 3 = both IADL and PADL problems.

In the H70 study (study 3) ADL was measured by a scale with a range from 0 to 41 (Hultén et al. 1969), where a high score signifies an extensive need for care and dependency on others. The items included in the scale are mainly related to PADL such as bathing, dressing, using the toilet, getting in and out of bed, and eating.

In the fourth study, based on the NONA study but with proxy interviews, proxies were also asked to estimate how the old individual had managed their household (3 = totally independent, 2 = somewhat dependent, and 1 = totally dependent) and personal care (3 = totally independent, 2 = somewhat dependent, and 1 = totally dependent) one year, six months, and one month before their death.

**Patterns of informal and formal care** in the home of the elderly were only analyzed in studies on the NONA sample. It was measured by questions about whether the respondents got assistance with IADL (cleaning their home, shopping, transportation, and cooking) or PADL (bathing, dressing, using the toilet, getting in and out of bed, and eating). They were also asked if the assistance came from informal sources, formal sources, or both. In some analyses the patterns of care, both formal and informal, ranged from 0 – 10 where higher values indicated more use of care (with more ADL tasks). For some analyses another scale was used: 0 = no use of care, 1 = use of informal care only, 2 = use of formal care only and 3 = use of both informal and formal care. It should be noted that *formal sources* only includes assistance from staff in Home Help services or in institutional care. Sources such as meals on wheels, transportation service, and more, are not included, nor are medical services or service from private sources. In the fourth study the proxies were asked to estimate the use of formal and informal care, with the household and with personal care one year, six months and one month before their death.

Information about **institutionalization** was collected in the NONA material by simply asking about how they lived at the time of the interview.

In the H70 study the information about institutionalization was obtained from both the home interview and from death certificates. The information was used to construct two variables. The first was the permanent place of residence at time of death - institution or the community. In the H70 study the information was also collected to analyze the age at which respondents were institutionalized, if so.

## 4. Results

### 4.1. Study I. Factors related to care pattern in Swedish oldest old

#### 4.1.1. Introduction and aim

In the first study the aim was mainly to give a description of the sample of the oldest old in the NONA study and to analyze associations among actual and perceived health, actual and perceived social networks, guided by the resource theoretical model. The purpose was also to analyze how the oldest olds' resources were related to ADL function, and patterns of formal and informal care, including institutionalization.

#### 4.1.2. Method and analyses

Interviews were performed in the places of residence of the NONA sample described above by trained, registered nurses. Chi-square, independent samples t-test, Fishers exact probability test and Pearson correlation were performed for the descriptive part of the study. A multinomial logistic regression was performed to seek factors related to patterns of care including only respondents living in the community (n = 102). The dependent variable was patterns of care coded as: *use of informal care* (1), *formal care use only* (2), *use of both informal and formal care* (3), and further *no care* was used as reference category (0). The objective and subjective health indexes, and objective and subjective social network indexes, and finally ADL scores were included as covariates (for this analysis ADL was coded as 0 = no ADL problem, 1 = only IADL problems, 2 = only PADL problem, 3 = both IADL and PADL problems). To find association between ADL, health, social network and institutionalization in the total sample (n = 157) a binary logistic regression was performed. The dependent variable was if the elderly individual was living in an institution (1) or living in the community (0). The resource indexes were added in a first step and ADL, coded as in the multinomial regression, was added in the second step.

Another attempt was to seek if ADL mediated any of the effect from the resources of the individual on formal care patterns (not included in the submitted manuscript). To try this, two linear regression analyses of the NONA sample at baseline (N =157) were performed; one to seek

factors related to functional ability and a second to find factors related to use of formal care. The NONA study is judged an adequate sample to try this idea since the study is designed to fit the resource theoretical model. The first regression analysis used ADL function (range from 0 to 10 including both IADL and PADL) as dependent variable. One would assume from previous research that age, gender and marital status as demographic variables would be related to ADL function, but gender and marital status showed no correlation with functional ability. Therefore age was used as the only sociodemographic variable (Rovine et al. 1988) in addition to the indexes of objective and perceived resources of health and social network. In the second linear regression model, use of formal care (ranged from 0 – 10 based on the ADL items) was used as dependent variable, with the purpose to find factors related to patterns of care, in addition to ADL. It should be clarified that in this analysis the definition of formal care by default includes care given by staff in institutions, where all of the respondents (55) were assumed to use some kind of formal care. The resource categories were used as independent variables in step one, together with age. In the second step ADL was added as an independent variable to see if the resource categories accounted for variance by themselves and/or to reduce associations found between the different measures, that is, whether they mediate the effect. An equation provided by MacKinnon and Dwyer (Equation 2.1, 1993) was used to determine the degree to which the mediator (ADL) explained the direct effect of independent variable (IV) on the dependent variable (DV).

Equation 2.1:

$$\text{Percentage of total effect mediated} = \frac{\beta_{(\text{mediator to DV})} \times \beta_{(\text{IV to mediator})}}{\beta_{(\text{mediator to DV})} \times \beta_{(\text{IV to mediator})} + \text{direct effect}_{(\text{IV to DV})}}$$

### 4.1.3. Results

The descriptive analyses demonstrated that subjective health and subjective social network, and especially ADL function, differed significantly between the individuals that lived in the community compared to institutionalized respondents. For subjective health, such differences were found in all three items and for perceived social network, the differences were found in all items but the question concerning confidants. No differences were found between institutionalized respondents and those living in the community, nor in the indexes of objective social network or in objective health (see Table 3). Neither were there any such differences in the

specific items in the index of objective social network, but the institutionalized respondents used more drugs and had more often visited a general practitioner during the last two years. Further, institutionalized respondents had significantly more problems in performing IADL and PADL tasks.

There were no gender differences in health, social network or ADL with one exception: the question on confidants. Men tended to report more confidants than women ( $\chi^2 = 6.14, p < .05$ ). When the respondents were separated into married vs. not married (never married, divorced and widowed) the significant effect of gender on the presence of confidants remained, but only within the married group (Fisher's EPT,  $p < .05$ ). In the *not married* group, there was no effect of gender on confidant status.

There was a low but significant correlation ( $r = .24, p < .01$ ) between respondents' perceived health and the more objective estimation of health, but not between objective and subjective social network ( $r = .16, ns$ ). ADL was highly and significantly correlated with subjective health ( $r = -.57, p < .01$ ) and subjective social network ( $r = -.40, p < .01$ ). ADL also had a significant but low association with objective social network ( $r = -.24, p < .01$ ), but there was no significant association between ADL and objective health ( $r = -.15, ns$ ). Moreover, 62% of respondents reported that they received some kind of assistance. Since elderly persons living in institutions more or less always get formal assistance, regardless of their problems with ADL, pattern of care was analyzed separately for elderly living in institutions and elderly living in the community. For those living in institutions, there were no differences in type of ADL problems in relation to the type of assistance the respondents received ( $\chi^2 = 1.38, ns$ ). Respondents living in the community, on the other hand, were more likely to receive informal care if they only had IADL problems, and were more likely to receive formal care if they also had problems with PADL ( $\chi^2 = 42.18, p < .01$ ).

The nominal regression analysis, based on community-living individuals ( $n = 102$ ), showed that subjective health and ADL function were significantly related to use of informal care only and formal care only whereas objective health and ADL were related to use of a combination of both informal and formal care. The binary logistic regression, including all respondents ( $n = 157$ ) showed that ADL was the only factor significantly related to institutionalization in this sample of the oldest old.

**Table 3.** Mean values in health, social network, and ADL, and frequencies of use of help in elderly persons living in the community or in institutions

	Community (n = 102)	Institution (n = 55)	T / $\chi^2$
<b>Objective health<sup>a</sup></b>	1.16	0.95	t = - 1.46
Number of symptoms <sup>a</sup>	4.5	4.2	t = - .52
Number of drugs <sup>a</sup>	4.9	7.0	t = 3.45 **
Visited hospital <sup>b</sup>	45	21	$\chi^2 = .12$
Visited general practioner <sup>b</sup>	85	45	$\chi^2 = 5.29 *$
<b>Objective social network<sup>a</sup></b>	9.56	8.21	t = - 1.94
Meet with children <sup>c</sup>	38	17	$\chi^2 < .01$
Telephone contact children <sup>c</sup>	65	22	$\chi^2 = 4.01$
Meet with relatives <sup>c</sup>	5	3	$\chi^2 = .28$
<b>Subjective health<sup>a</sup></b>	4.21	3.10	t = 3.79 **
Good general health	63	20	$\chi^2 = 11.20 **$
Health better than others	65	23	$\chi^2 = 7.85 *$
Health does not prevent me	39	12	$\chi^2 = 9.4 **$
<b>Subjective social network<sup>a</sup></b>	5.56	4.60	t = - 2.70 **
Belong to circle of friends	45	7	$\chi^2 = 16.74 **$
Have friends	60	10	$\chi^2 = 18.62 **$
Have confidants	27	7	$\chi^2 = 1.75$
<b>ADL (range 0 – 10)<sup>a</sup></b>	8.3	3.5	t = 7.94 **
IADL (range 0 – 4) <sup>a</sup>	0.75	3.05	t = 9.52 **
PADL (range 0 – 6) <sup>a</sup>	0.63	2.88	t = 7.69 **

<sup>a</sup> = mean value

<sup>b</sup> = yes

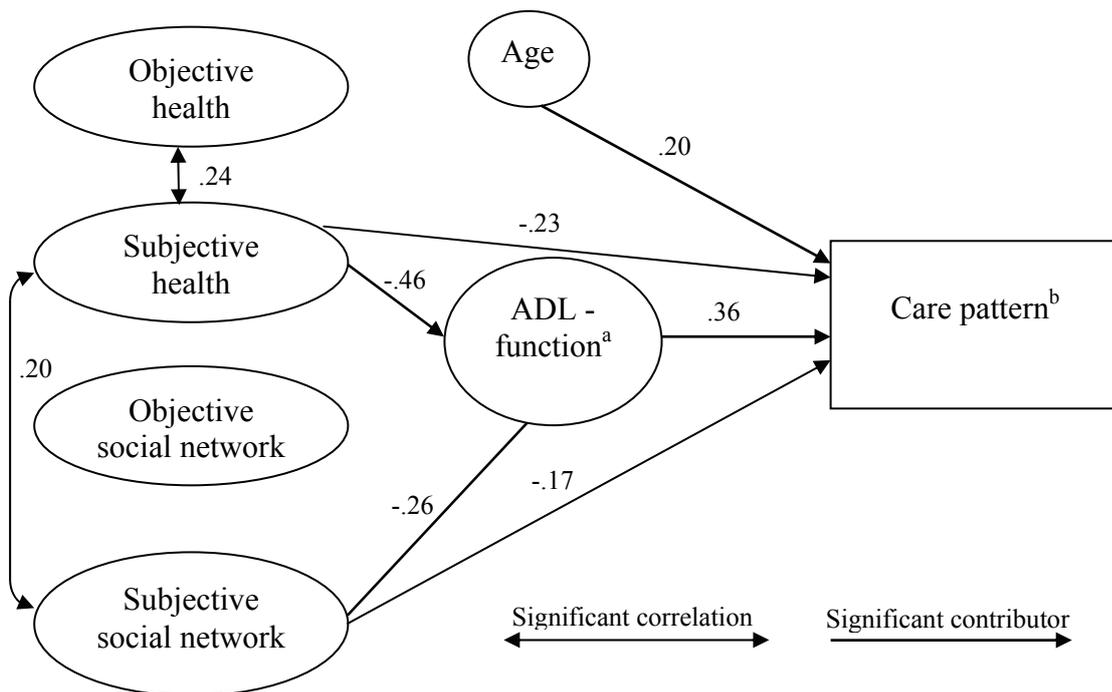
<sup>c</sup> = several times a week

<sup>d</sup> = to great extent

\* p < .05

\*\* p < .01

The results from the two linear regressions, performed to try the mediating effect from ADL, could be summarized as in Figure 2. Age was related to patterns of formal care, but not to ADL and the mediating effect was therefore not analyzed. Perceived resources were related to both ADL and use of formal care, but the objective resources were not. When adding ADL as independent variable towards patterns of care, subjective health and subjective social network turned non-significant and age and ADL were the only significant predictors in the model. On the basis of the two regressions, the mediating effect from ADL was analyzed as described above, and it demonstrated that ADL mediated the effect of perceived health (42%) and perceived social network (35%) on use of care. The objective social network was related to use of care, when ADL was added as independent variable in the model, but it was not significant related to ADL according to the first linear regression, and the mediating effect was not analyzed. To conclude, it seems that ADL works as a mediator to some extent for the subjective resources in this sample of the oldest old.



<sup>a</sup> Range from 0 – 10 where higher values indicates more ADL problems

<sup>b</sup> Range from 0 – 10 where higher values indicates more use of formal care

*Figure 2. The pattern of ADL and use of formal care.*

#### **4.1.4. Conclusion**

The major conclusion from the first study was that the perceived resources seem to affect patterns of care and institutionalization to a greater extent than the more objective ones in this sample of the oldest old. The differences in subjective health and subjective social network between institutionalized respondents and those living in the community however did not show any effect on institutionalization in the logistic regression. The oldest old living in the community and having IADL problems were more likely to receive informal assistance, but if they had PADL problems they more often got formal care. ADL was the strongest predictor for both use of care and institutionalization, but perceived health was related to use of informal care only and formal care only. Social network contacts were not related to informal care use, which could indicate that most informal care is received from spouses and it would therefore not be affected by contacts with children and relatives. ADL and objective health together were related to the use of a combination of informal and formal care, indicating that in the presence of severe health problems in the elderly individuals require both forms of care. The strong effect from ADL on all care patterns indicates efficient targeting of the formal care system in Sweden but the results also demonstrate a mediating effect of ADL on the subjective resources.

## **4.2. Study 2. Health, functional capacity, formal care, and survival in the oldest old: A longitudinal study**

### **4.2.1. Introduction and aim**

The general hypothesis pertaining to terminal decline maintains that a decrease in function, such as health, is not primarily related to chronological age but rather to distance to death. Hence, it should be possible to predict survival or death, based on the change in different functions. Due to the relatively short remaining survival time for the population of the oldest old, it is of great interest to relate both subjective and objective health, and ADL, to terminal decline and survival. What is more, with regard to the growing number of oldest old it is often assumed that the use of both formal and informal care will increase worldwide. In Sweden the number of elderly receiving both formal and informal care has increased between 1994 and 2000. The aims of the second study were to investigate how health, social network, ADL, and use of care change over time (four years) and to analyze how differences in health and ADL affect the survival of the oldest old.

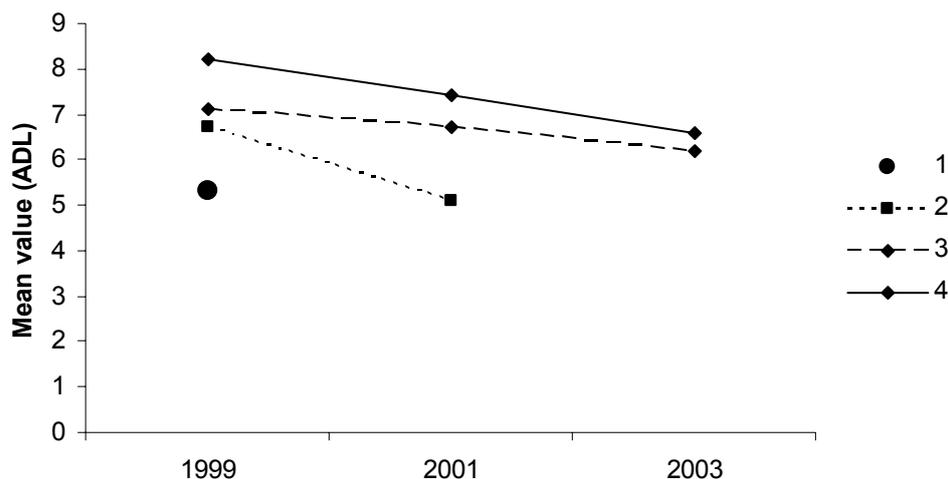
### 4.2.2. Method and analyses

As in the first study the second study is based on data from the NONA sample. In comparison to study one, this analysis of the sample was longitudinal. The analyses are based on answers in the first wave, from 157 oldest old individuals, from 98 persons in the second wave and 62 in the third. One-way ANOVA was used to determine differences (from the first in-person testing [IPT1] in 1999) between four different groups of survival: 1 = Deceased before wave 2 ( $n = 38$ ), 2 = Alive at wave 2 but deceased before wave 3 ( $n = 35$ ), 3 = Alive in wave 3 but deceased within two years after wave 3 ( $n = 36$ ), 4 = persons who survived at least two years after the third in-person testing in 2003 ( $n = 48$ ). Repeated measures (General Linear Model) were performed to analyze changes longitudinally over the four year period ( $n = 62$ ). Pearson correlations were used to determine associations among objective and subjective health, ADL, and use of informal and formal assistance/care. The final step was to determine factors related to survival in this age group of the oldest old using the Cox proportional hazard regression model.

### 4.2.3. Results

The repeated measures ( $n = 62$ ) demonstrated a significant decline in objective health over the three waves ( $F = 10.36$ ,  $p < .01$ ), but there was no similar change in subjective health ( $F = .51$ , ns). Even so, objective health and subjective health were significantly correlated to each other at all three waves; 1999:  $r = .33$ ,  $p < .01$ ; 2001:  $r = .44$ ,  $p < .01$ ; 2003:  $r = .38$ ,  $p < .01$ . Further, there was a decline in the ability to perform total ADL over the three waves ( $F = 9.70$ ,  $p < .01$ ) (Figure 3), which concerned both IADL ( $F = 9.03$ ,  $p < .01$ ) and PADL ( $F = 6.04$ ,  $p < .01$ ).

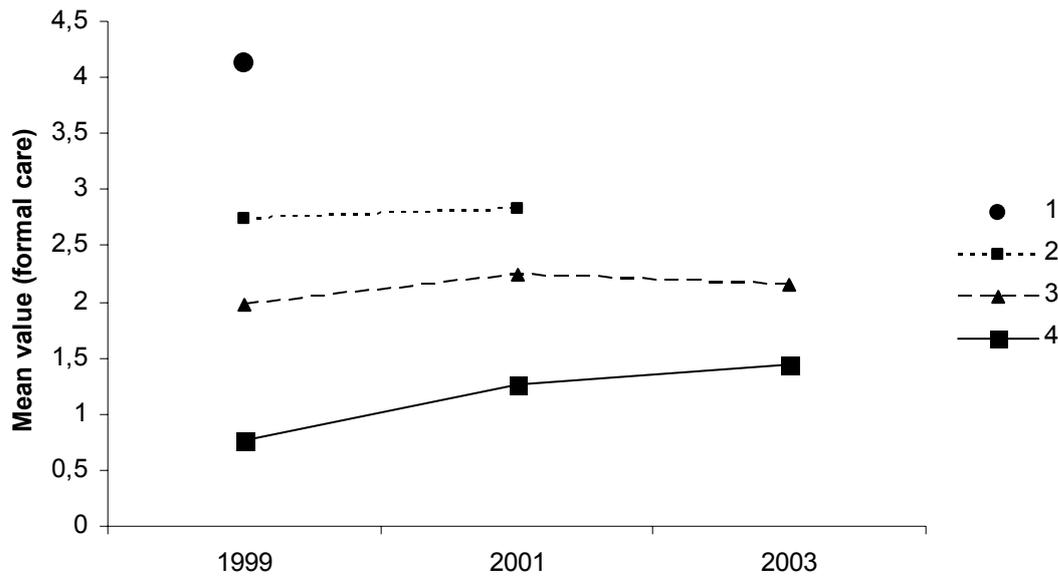
Objective health was not significantly correlated with ADL at any time: 1999:  $r = .27$ , ns; 2001:  $r = .16$ , ns; and 2003:  $r = .06$ , ns. Subjective health, however, was correlated with ADL in 1999 with  $r = .54$ ,  $p < .01$  and in 2001 with  $r = .58$ ,  $p < .01$ , but not in 2003 with  $r = .32$ , ns.



**Figure 3.** Mean value of ADL followed over three years separated into the four categories of survival status. 1 = Died before wave 2; 2 = Died before wave 3; 3 = Died within two years after wave 3; 4 = Alive two years after wave 3.

For the thesis, the interpersonal resource categories were also analyzed longitudinally, but they are not presented in the article. The repeated measures demonstrated a significant decline in subjective network factors ( $F = 5.14$ ,  $p = .01$ ) but stability in the objective social network factors ( $F = 2.97$ , ns). The decline in the subjective social network index was explained by decline in feelings of having acquaintances ( $F = 4.59$ ,  $p < .05$ ) but not by feelings of belonging to a circle of friends ( $F = 2.6$ , ns) or feelings of having confidants ( $F = 1.82$ , ns). Frequency of personal contacts with children ( $F = 1.52$ , ns) and relatives ( $F = .32$ , ns) remained stable. Frequencies of personal contacts with friends declined significantly ( $F = 5.57$ ,  $p = .01$ ).

The use of total care, both formal and informal, increased significantly ( $F = 8.26$ ,  $p < .01$ ) over the four years, but the trend seems to be explained by the increase in formal care ( $F = 11.18$ ,  $p < .01$ ) as demonstrated in Figure 4; there were no significant differences in the use of informal care ( $F = 1.90$ , ns) over time.



**Figure 4.** Mean value of use of formal care (range 0 – 10, where higher values indicate higher use) followed over three years separated into the four categories of survival status. 1 = Died before wave 2; 2 = Died before wave 3; 3 = Died within two years after wave 3; 4 = Alive two years after wave 3.

Once the oldest old entered the formal old-age care system, it was rare that they returned to independent living. ADL was highly and negatively correlated with use of formal care during all three waves (1999:  $r = -.88$ ,  $p < .01$ ; 2001:  $r = -.81$ ,  $p < .01$ ; 2003:  $r = -.60$ ,  $p < .01$ ), the lower ADL function, the more formal care they received. Informal care was only correlated with ADL in 2003 ( $r = -.60$ ,  $p < .01$ ). Subjective health was significantly correlated with formal care in 1999 ( $r = -.48$ ,  $p < .01$ ) and in 2001 ( $r = -.40$ ,  $p < .01$ ) but not in 2003 ( $r = -.07$ , ns). Objective health showed no significant association with formal care at any wave (1999:  $r = -.13$ , ns; 2001:  $r = -.19$ , ns; 2003:  $r = -.22$ , ns).

Differences were found at baseline (1999) between the four groups of survival status in objective health ( $F = 3.86$ ,  $p < .05$ ), subjective health ( $F = 4.71$ ,  $p < .01$ ) and in ADL function ( $F = 4.6$ ,  $p < .01$ ), IADL ( $F = 3.3$ ,  $p < .05$ ), and PADL ( $F = 4.9$ ,  $p < .01$ ), where survivors had significantly better health and ADL function than those who died early. The Cox regression model showed that objective health and ADL functioning significantly predicted survival, but age and subjective health did not.

#### **4.2.4. Conclusion**

Conclusions to be drawn are that there was a significant decline in objective health and ADL, a decline that was related to mortality, but no such trend of decline was found in subjective health. However, survivors estimated their health as significantly better at baseline which could indicate an expression of decline in perceived health in relation to death even if the pattern of terminal decline was more apparent in objective health and ADL. Furthermore, the decline in ADL function was highly correlated to the increase in use of formal care.

### **4.3. Study 3. Sooner or later in institutions in late life**

#### **4.3.1. Introduction and aim**

Existing information about institutionalization of elderly individuals is based mainly on cross-sectional data and does not address the cumulative risk of institutionalization. The purpose of the present study was to prospectively analyze longitudinal data and estimate the risk of institutionalization from age 70.

#### **4.3.2. Method and analyses**

This study was based on the H70 study, described above, where the respondents were followed from 70 to 100 years of age. Three different analyses were performed: a descriptive prospective analysis, cross-sectional analyses at ages 70, 79, and 85 years, and a longitudinal analysis of predictors for institutionalization, using Cox regression model with time-varying variables. In the prospective analyses chi-square tests and independent samples *t*-tests, were performed to evaluate differences between those who became permanently institutionalized at any point after the baseline measure and those who did not. Chi-square test and independent samples *t*-test were also used in the cross-sectional analyses to analyze differences between those who resided in an institution at ages 70, 79, and 85 years and those who did not. Cox regression model with time-dependent covariates were used to evaluate factors related to institutionalization from baseline, at age 70 years, and over the next 30 years. Time was measured as the number of years that respondents lived in the community, beginning at age 70 years until institutionalization or death. The status/event was whether or not the respondent was permanently institutionalized at any

time from age 70 years up to age 100 years. Most of variables we tested were considered time-dependent: marital status, number of medications, number of symptoms, feeling healthy or not, contact with children, contact with individuals outside the family, satisfaction with contact with children, feelings of loneliness, and ADL function. Gender, SES, and having children nearby were considered stable. The Cox regression model was built in three steps with the sociodemographic variables gender, marital status, and SES in the first block. In the second block, health and social network variables were added, in an attempt to determine the unique contribution of these covariates, separate from ADL. For the third and final block, ADL was added, since it is considered a strong predictor of institutionalization. For the thesis separate Cox regression model were performed for men and women, but they are not presented in the submitted manuscript. In the separated Cox regression models indexes of resources were used as co-variables. Objective health included the variables number of symptoms/diseases (0 = three or more symptoms/diseases, 1 = 1 – 2 symptoms/diseases and 2 = no symptoms/diseases) and number of drugs (0 = four or more drugs, 1 = 1-3 drugs and 2 = no drugs). Subjective health was measured with one question; “Do you feel healthy?”. Objective social network included three questions: *if the respondent had children living nearby* (0 = no, 1 = yes), *how recent the respondent had met his or her children* (0 = no children or more than one month ago, 1 = one to four weeks ago, 2 = this week) and *if they had daily contact with others than their spouse or co-resident* (0 = no, 1 = yes). Subjective social network was measured by the following items; *feelings of loneliness* (0 = often feels lonely, 1 = sometimes feels lonely and 2 = never or seldom feels lonely) and *if the respondents felt that they met with their children as much as wished for* (0= never have contact/no children, 1 = too often or too seldom, 2 = just as much as I wish for).

### **4.3.3. Results**

The prospective analysis indicated that 50% of the individuals eventually moved to an institution. Significantly more women than men were institutionalized, although for women, the move occurred later in life. Table 4 illustrates prospective risk of institutionalization for different groups based on sociodemographic factors (not in the manuscript). It demonstrates that not only do females run higher risk for institutionalization but it also seems that men are more protected against institutionalization by marriage. Furthermore, those gender differences could be found with regard to SES as high SES seems to have a protective effect for men while women with high SES faced as high risk of institutionalization as did women with low SES. Never married women

with low SES face the highest risk of institutionalization, according to Table 4. It should be noted however that this is a very small group.

ADL is known to be one of the most important predictors of institutionalization and ADL declined significantly between age 70 and age 85 ( $F = 24.46, p < .001$ ) with the most rapid decline between ages 79 and 85. There were no gender differences in ADL at the age of 70 ( $t = -.46, ns$ ), 79 ( $t = .33, ns$ ) or 85 ( $t = .38, ns$ ).

The cross-sectional analyses demonstrated that different factors were important to institutionalization at different ages. For example there were only gender differences between institutionalized and non-institutionalized respondents at the age of 85, and differences in subjective health and subjective social network at the age of 79. The only factors that differed significantly between institutionalized respondents and those living in the community at all three ages (70, 79 and 85) were SES, number of medications and social contacts with others than spouse.

**Table 4.** Proportion (%) of different groups that at some point moved to institution

	SES				Marital status		
	Lowest quartile	Medium	Highest quartile	Never married	Married <sup>a</sup>	Never married & low SES	Married <sup>a</sup> & high SES
Total							
Men	41	53	36	59	40	70	37
Women	57	55	59	69	55	79	54
Total	50	54	59	67	47	76.5	44
N (total number of respondents in the different groups)							
Men	448	91	225	126	32	415	10
Women	516	158	246	104	94	420	87
Total	964	249	471	230	126	835	210

<sup>a</sup> presently or previously

The Cox regression model with time-varying covariates indicated that gender, socioeconomic situation, marital status, number of symptoms, having children living nearby, and activities in daily life were related to institutionalization. Since Table 4 demonstrated gender differences, separate Cox regression models for men and women were performed (not in the manuscript). They demonstrate that there are gender differences in factors related to institutionalization (Table 5). For men marital status, SES, objective health and ADL were significant predictors of institutionalization in the final model whereas for women SES, objective social network and ADL were significant predictors.

#### **4.3.4. Conclusion**

The conclusions drawn from this study are that the proportion of elderly persons who were institutionalized was significantly higher than that generally found in cross-sectional studies. In addition, the cross-sectional analyses demonstrated that different factors were related to institutionalization at different ages. Furthermore, in contradiction to the first study of NONA, the sociodemographic variables, gender, marital status and SES, in addition to the more objective resources of having children living nearby and number of symptoms predicted institutionalization during a subsequent 30-year period. There are gender differences in factors related to and protective of institutionalization that needs to be further investigated.



## **4.4. Study 4. End of life care in the oldest old**

### **4.4.1. Introduction and aim**

In Sweden approximately 50% of all deaths occur at age 80+ but most research on the end stage of life has focused mainly on young, middle aged or, at most, young-old people. The aim of this study was to describe the last year of life of a sample of the oldest old, focusing on care trajectories, health, social network and function in daily life activities.

### **4.4.2. Methods and analyses**

The data originated from the NONA study, a longitudinal study, during which 109 participants died during the four year study period. Approximately one month after their death, a relative was asked to participate in a telephone interview concerning the deceased person's last year in life. One hundred two relatives agreed to participate. In this study descriptive analyses such as chi-square test, *t*-test, and one-way ANOVA were used to assess differences in location at time of death. Pearson's correlation was used to examine correlations among changes in health, functional ability, and memory during the last year. Also, with the purpose to validate proxies' answers, they were matched with the oldest old individuals' answers from the last interview in which they had participated. There were 76 of the deceased NONA subjects participated in interviews on their own, and 26 participated entirely by proxy, even earlier in the main NONA study. Therefore, the correlation analyses of answers provided by proxies (after the oldest old individuals' deaths) and the elderly themselves were based on 76 cases (Table 6).

**Table 6.** Correlations among proxies' estimates and the old individuals' last response in the NONA study (n = 76).

The old individuals' last response	Objective health	Subjective health	IADL	PADL	Objective social network	Subjective social network
Proxies' estimations						
Health						
One year prior to death	-.19	.44 **				
Six month prior to death	-.27 *	.40 **				
One month prior to death	-.11	.35 **				
Managed their household						
One year prior to death			.72 **			
Six month prior to death			.66 **			
One month prior to death			.61 **			
Managed their personal care						
One year prior to death				.61 **		
Six month prior to death				.61 **		
One month prior to death				.07		
Social network					.50 **	.27 *

\*\*\* p < .001, \*\* p < .01, \* p < .05

#### 4.4.3. Results

Most of the elderly in this sample of the oldest old (74.5%) died in an institution and their relatives were mostly satisfied with the end-of-life care and thought that the elderly received the care they needed. There were no significant differences in satisfaction with the care for elderly who died in hospital, elder care institution, or at home. There were however some, but not many, differences in health and social network, based on locations at time of death, see Table 7. Those

dying in institutions, for example, had fewer social contacts than those dying in a hospital or at home.

**Table 7.** Description of NONA participants by the location at the time of death

Died at:	In the community n = 5	Institution n = 76	Hospital n = 21	
Mean age	91	93	91	F = 2.49
Gender				$\chi^2 = 1.97$
Men	2	20	9	
Women	3	56	12	
Marital status				$\chi^2 = 2.36$
Married	2	6	6	
Widowed	3	65	14	
Never married	0	5	1	
Social network (mean value)	5.80	5.43	3.12	F = 12.63**
Personal contact <sup>a</sup>				F = 14.34*
At least once a week	5	51	19	
Once a month or less	0	9	1	
Telephone contact <sup>a</sup>				F = 15.77**
Once a week or more	4	22	18	
Once a month or less	1	36	2	
Contact with relatives				F = 2.24
Yes, several	3	33	15	
Yes, one	1	15	2	
No	1	27	5	

<sup>a</sup> with children, n = 86, \* p < .05, \*\* p < .01

Further, significantly more of the elderly who suffered from dementia or similar symptoms died at elder care institutions ( $\chi^2 = 15.54$ ,  $p < .01$ ) than those with no cognitive problems. There was a significant difference in the pattern of changes in health before dying, based on location at time of death ( $\chi^2 = 10.93$ ,  $p < .05$ ); three of those dying at home died a sudden death, and all six elderly individuals whose health had been reported fluctuating were staying at institutions at the time of death. Nevertheless, the proxies estimated that the health steadily decreased during the last year of life in most cases, and reported that there was a decline the oldest old functioning of daily life activities.

#### **4.4.4. Conclusion**

The major conclusions to be drawn from the results are that the care at end of life in the oldest old is challenged by the problems of progressive declines in ADL and health, which make it hard to accommodate the oldest old who are dying in the palliative care system. The findings also highlight the need to support social networks at elder care institutions and arrange special palliative care for this group of oldest old due to the results of fewer social contacts for those dying in institutions.

## 5. Discussion

The aim of this dissertation was to evaluate factors related to patterns of care in the oldest old guided by a resource theoretical model. Two different longitudinal studies were used, and different designs: the first study was cross-sectional, the second longitudinal, the third had longitudinal, a cross-sectional and prospective components, and in the fourth study, proxy interviews were used to describe the last year in life of the oldest old after they deceased. To guide the analyses the resource theoretical model introduced by Malmberg (1990) was used, and objective and subjective health and social network measures were included defined as resources. In all four studies ADL was included, as an indicator of when resources fail to meet the demands from the environment, resulting in the outcome: variations in patterns of care. The results confirm the idea from the resource theoretical model: that perceived and actual resources capture different dimensions and that they affect patterns of care differently at different ages. Perceived resources seem to have a greater effect on patterns of care than the more objective in the sample of the oldest old. However, the sociodemographic variables, gender, marital status and SES in addition to the more objective resources had greater impact on institutionalization in the H70 study, with the inclusion age of 70. Still, ADL was strongly related to patterns of care and institutionalization in both samples which indicates an effective targeting by the formal care system in Sweden, based on needs.

### 5.1. The role of resources

The major aim of this thesis is to determine the effects of actual and perceived resources on patterns of care. The two materials (H70 and NONA) yielded different results concerning actual and perceived resources. The study on the H70 material revealed that, in addition to sociodemographic variables, objective resources had the highest impact on institutionalization, even if the importance of them differed between men and women. On the other hand, in the first cross-sectional analysis of NONA, in addition to ADL, subjective resources were most strongly related to institutionalization and pattern of care. Of course, the different measures can have an impact on the result, but it is also possible that the objective resources are of greater importance in “younger” ages (meaning from 70 and 85 years), whereas the subjective resources are more essential in advanced ages.

### **5.1.1. Individual resources defined as health**

Adaptive processes might partly explain why the perceived resources do not have the same effect at the age of 70 as they do at the age of 90. That is, the more objective resources are not as adjustable as the subjective resources are in older age. Leinonen et al. (2001b; 2002) suggested that older people adapt to changes in their objective health and functional capacity. They based it on the result that even if there was an increase in chronic diseases and decline in functional performance in the elderly individuals in their study, the subjects assessed their health similarly over the years they were followed. The sample in that study was younger (75 years at baseline) than the sample in NONA, but the results are similar to the second study, and the centenarians in Jopp and Rott's (2006) study showed similar patterns. In the longitudinal analysis of NONA (study 2) the objective health and ADL function decreased significantly but there was no such trend in subjective health. However, perceived health was strongly related to function in ADL (shown in both study 1 and study 2). This result confirms the suggestion that adaptive processes take action in advancing age. It is possible, as discussed by Leinonen et al. (2002) that individuals in very advanced age consider their declined functions as normal ageing and accordingly adjust their standard of good health. Age-related deteriorations are often slow and progressive and the oldest old individuals might adjust their norms gradually, and simultaneously adjust their own rating of their health. This argument is similar to that of Kivett et al. (2000), who suggested that the oldest old evaluate their health status relative to that of their aging peers rather than to their own health status. That is, there is probably a change in the frame of reference with advancing age. Jopp and Rott (2006) suggested yet another explanation: even if the oldest old feel restricted in their everyday life they develop ways to detach themselves emotionally from the deteriorated state of their body.

It could further be assumed that perceived health in the oldest old is affected by interpersonal and institutional resources, important for dealing with future illness. Idler and Benyamini (1997) suggest that self-rated health may more accurately reflect the adequacy of resources, such as income, education and social networks to meet future needs, than their absolute value. That is, when rating health the oldest old do not only consider medical and functional indicators of health but also interpersonal and institutional resources. The results from the NONA study demonstrate not only stability in perceived health and the importance of it on the actual pattern of care, but also that perceived health is more strongly related to perceived social network than to the more objective measure of health. Those results could confirm the suggestion from Due et al. (1999) that perceived social support is the most important concept in relation to health. The

results could further indicate that perceived health is not only related to present patterns of care, but also that the oldest old take into account the future need when estimating their health. Lack of friends and confidants to rely on when needs increase would affect perceptions of health and would affect ADL function, as demonstrated by Braungart (2005). Dunér and Nordström (2007) demonstrated the importance and value of having confidants and emotional support because they contribute to feelings of belonging, security and wellbeing. In conclusion, adaptive processes, frame of reference changes and interpersonal and institutional resources might have impact on subjective health. This could explain why self-rated health remains stable in oldest old individuals, despite declines in objective health and ADL function. As well, it highlights the importance of considering circumstances other than health in the oldest old when discussing their patterns of care.

### **5.1.2. Interpersonal resources as in social network factors**

The measures of health in the NONA study and in the H70 study are quite similar. In both samples, the respondents were asked to estimate their health and variables such as number of drugs used and number of symptoms of illness. The social network questions differed to some extent, and thus the different results are not surprising. It is also difficult to argue that the inclusion age had the same impact as in health. One could however discuss if adaptive processes, similar to those in health, take part concerning the subjective social network. There was a decline in feelings of having acquaintances and frequency of personal contacts with friends by the oldest old. Still they considered themselves to have confidants and belonging to a circle of friends. Those results could suggest that the oldest old adapt to changes in number of friends and adjust their social network situation by using their few remaining friends as “multipurpose”, as suggested by Field and Gueldner (2001) and McCamish-Svensson et al. (1999).

The result from the studies concerning feelings of having confidants is interesting from another point of view, due to the gender differences that were found. The sample in the NONA study is rather small, and only simple descriptive, non-parametric analyses were performed; nevertheless, men reported more confidants than women. What is more, the significant gender differences in reporting of confidants were found in the married group. Cavallero et al. (2007) reported similar results. They found that married women more often felt a lack of confidants in comparison to married men. It might be that men and women have different ideas about the meaning of confidants. Men may more often consider their spouse as a confidant whereas women may think of confidants more like friends. This suggestion is supported by the study of Due et al. (1999),

who showed that men report confidant relationships with their partner more often than do women. This result is important, especially in relation to the fourth study that suggested a decline in social network in the year prior death and also fewer social contacts for those elderly individuals dying at institution. Those gender differences and social network factors probably affect institutionalization, in addition to ADL and health (see discussion below). Even though social networks had low impact on care patterns in the NONA material, they were significantly related to ADL suggesting that there is an interaction between ADL ability and social networks. The negative correlation suggests that increasing ADL problems are associated with decreasing social contacts and diminished feelings of having acquaintances and confidants.

Considering the results from the fourth study, where the proxies of the deceased oldest old individuals estimated a decline in the strength of the social network during the last year, and considering that those dying at institutions had fewer social contacts, it could be assumed that the demonstrated functional decline negatively affected social contacts. In addition, a majority of the individuals who suffered from cognitive problems and dementia died at institutions, and those cognitive problems probably affected both ADL and the ability to maintain social contacts. Even so, the longitudinal analyses of social network in NONA demonstrated that declines were found only in the items concerning contacts with friends and having acquaintances, not in contacts with family or having confidants. It is not surprising that contacts with friends declines in advanced ages, and the feelings of belonging to a circle of friends would naturally decline as well. On the other hand, perhaps more important than frequency and number of contacts is the perception of having confidants to rely on and this item did not change over time in the NONA study, but there were gender differences. The perceptions of social network, which did change to some extent over time, did affect patterns of care and ADL more than the more objective measure of social network, which remained stable in the NONA sample. Firstly, this means that it is important that caring staff caring for terminal patients are aware of the quality of the social network of the oldest old, and do not only consider the number of social contacts. Even if the numbers of contacts with friends and relatives remains stable, it is importance to consider whether the oldest old individuals have friends or confidants because they serve different functions. There are signs that the oldest old married women do not confide in their husbands; as well, it is possible that the oldest old widowers have no one to confide in after the death of their wife. Secondly, the decline in social contacts outside the marriage during the last year of life might affect oldest old women, due to declines in possibility of informal assistance and in confidants. Because it is assumed that men more often received informal assistance from their wives and also saw them as confidants, declines in social network outside marriage might not

affect them as much as being widowed. Even if there were no significant decline in confidants in the NONA study the sample was too small to analyze men and women separately or to analyze according to marital status. Therefore this discussion is speculative due the results found and previous studies.

Nevertheless, both the NONA study and the H70 study established that social network factors are important influences on patterns of care, that there are gender differences in the importance of social network factors, and that objective and subjective social networks change and affect the care patterns differently in advanced age. As Whitaker (2004) demonstrated, the social network plays a very important role for the oldest old individual at the end of life care, both as confidants and as representatives of the elderly values and interests. The latter role is especially important when elderly individuals are not able to speak for themselves, due to cognitive problems and dementia for example. In the fourth study, the results demonstrated that many of the elderly dying at institutions suffered from dementia and had weaker social networks. Therefore, the staff caring for these patients has the serious task of investigating the social network situation for the elderly, determining whether they have someone to talk to, or have someone to speak for them. Research (National Board of Health and Welfare 2007) has demonstrated that staff has limited knowledge about the elderlies' thoughts and feelings about death, and that the elderly lacked someone to talk to and to share their life experiences.

## **5.2. Interaction of sociodemographic variables and resources of the oldest old**

In addition to the resource categories, gender, marital status, and SES had various but interesting effects on patterns of care. In the H70 study for example, marital status and gender were strongly related with institutionalization but not in the NONA-study. The effect of sociodemographic variables could be seen in the Cox regression analyses of the third study of the H70-sample and the importance of the sociodemographic variables on future institutionalization was also shown Table 4. Table 4 was modeled on tables presented in a previous analysis of institutionalization risk conducted in two separate regions in Scandinavia. The institutionalization pattern in the H70-study was similar to those reported in Sundström's et al. (2003) study. They used data from persons living in a rural area in southern Sweden who turned 67 in 1969-70 and from all persons  $\geq 80$  years living in a small town in Norway. More than 32% of the studied population in the

first area and more than 70% in the second area were eventually institutionalized. Obviously, the inclusion age of elderly respondents in a study of institutionalization is important. It is possible that if the starting age was younger, there would be fewer cases of institutionalization, and at older ages, institutionalization would be more common. This notion was confirmed by the fact that, in the study by Sundström et al. (2003), the effects of gender, marital status, and SES were greater for 67-year-olds than for the  $\geq 80$ -year-olds, which was probably due to the greater frailty in the older age group. In the third study in this thesis, the inclusion age was 70 years, and gender, marital status and SES, as well as objective health, objective social network and ADL were predictors of institutionalization. In the NONA study the inclusion age varied between and 94 years, which could explain the lack of effect on patterns of care and institutionalization from the socio-demographic variables. At those ages, as indicated from the study by Sundström et al. (2003), other factors might have taken over the majority role.

As shown in Table 4 from study three, not only did females have a higher risk for institutionalization but it also seems as though marriage was more protective against institutionalization for men than for women. Other research has demonstrated similar results (Arber 2004; Grundy and Jitlal 2007; Romören and Blekeseaune 2003) and the explanations for the gender differences in institutionalization and protection from marriage vary. One of the most common explanations is that females live longer and therefore have a longer period of disability but also that they have a longer period of widowhood (Arber 2004; Romören and Blekeseaune 2003). Arber (2004) demonstrated that 45% of men aged 85 or more were married (in the UK), compared to 10% of the women, and suggests that some of the gender inequalities among elderly people might be due to marital status rather than gender per se. The fact that men are more likely to have a living spouse in old age might reduce their use of formal services, because of the informal care given by their wife as demonstrated by Romören and Blekeseaune (2003) and Hellström and Hallberg (2001). The later study demonstrated that not only did wives help husbands significantly more than the other way around, but also that children helped out more in older age groups. They concluded that most informal care takes place among elderly couples and that children are more involved in the informal assistance of women. They further suggest, similar to Romören and Blekeseaune (2003), that this fact is more due to longevity of women than to gender issues. Grande et al. (1998) on the other hand reported that women were less likely to die at home, suggesting that gender roles play a role and that men are less efficient as carers. But, in NONA there were no gender differences, nor any differences in marital status, between institutionalized respondents and those who were not. Furthermore, there were no gender differences in ADL function in either NONA or H70. This suggests that perhaps one has

to look beyond the hard facts of longevity and disability of women to get a clearer picture of the role of gender and marital status and their effect on institutionalization.

Avlund et al. (1998) suggested that men seem to benefit more from living with others and from being married than do women. Their discussion regarded protection from mortality, but the argument could be applied to protection against institutionalization as well. They (op sit.) suggested that for men the essential variable is to be married and to have their wives in their social network. Men's greater reliance on a single confidant in combination with a shrinking social network with advancing age makes them more vulnerable than women. In addition to longevity and disability, their discussion touches on another interesting aspect of gender differences that might affect patterns of care. The first study on the NONA sample indicated that women and men have different opinions about whether their spouse is a confidant or not. Men tended more often to see their wife as a confidant. If this is true, it could be assumed that men receive greater protection against institutionalization from marriage than do women. In addition, never-married men would be more vulnerable to institutionalization due to lack of social network protection. For women, their spouse is maybe not the only confidant, if he is considered as a confidant at all. Therefore, husbands do not offer the same protection for women as do other social contacts. This explanation was further supported when analyzing men and women separately in two Cox regression models (Table 5). Table 5 shows that for 70 year-old men, marital status, SES, objective health and ADL function predicted institutionalization but for women it was SES, objective social network and ADL. Thus, men got greater protection from marriage than women. On the other hand, women got protection from their objective social network (having children and number of contacts), and men did not. Therefore, the gender differences seen in institutionalization could be influenced by longevity, disability, and women as more frequent caregivers, but the social network factors might play an important role as well. The H70-study result could be interpreted as men having greater protection against institutionalization from marriage, women from contact with children. These gender differences in how social network affects institutionalization may be explained by the informal care provided by wives for men or by longevity for females but the gender differences in perception of social network also played a role. To conclude, the gender differences in institutionalization and the protective effect of marriage might be explained by gender differences in both objective and subjective interpersonal resources, and are not only due to the possibly higher likelihood of being a caregiver, or that women lives longer with higher rates of disability. Those gender differences and the important role of social network factors, also implies that men might be an underused resource for women and perhaps need to be encouraged to participate more in the care of their spouses.

Another sociodemographic variable that showed some gender differences was SES. High SES seemed to be protective against institutionalization, but for men only. As seen in Table 4 women with high SES faced as high risk of institutionalization than women with low SES, in men the pattern was somewhat different. Men with high SES were less likely to move to an institution than were men with low SES. On the other hand, those gender differences did not hold up in the stratified Cox regression analyses (Table 5) where SES significantly predicted institutionalization in all three models for both men and women. These results are puzzling. It is possible that there are benefits from a high SES that affect the institutionalization risk, such as better possibility of a healthy life style, affect health and functional ability. This has been demonstrated by Avlund et al. (2003c; 2004b) who found strong associations between material wealth indicators and health and functional ability. They also found that housing tenure was consistently related to health and functioning among men, whereas income was more consistently related to health and functioning among women. These results could help to explain the gender differences found in the SES effect on institutionalization. If females' health and functioning becomes worse, they would be more likely to move to an institution and as demonstrated, health and functioning among women are related to low income (one of two measures included in SES in this study).

The question is why these different trajectories emerge. Just as men's vulnerability is influenced by social network factors, Avlund (2004b) suggest that women's vulnerability might result from lower reserve capacity in most physiological functions and the cumulative effects of this disadvantage could have more serious consequences. Arber (2004) suggests that the decrease in income also reflect changes in marital status, and again the fact that women live longer as widowed. In the H70 study, the household income was measured. One explanation for the gender differences in the effect from SES on institutionalization might be that when women become widowed, the household income decreases; in combination with the lower reserve capacity in most physiological functions and cumulative disadvantage, it leads to institutionalization. It may indicate that Arber's (2004) suggestion that marital status and gender have an additive rather than interacting effect on institutionalization might be confirmed.

### **5.3. Interaction of ADL and resources of the oldest old**

ADL was highly related to the outcome in the three first studies, and has interesting implications with regard to the fourth. Ahacic et al. (2003) highlighted the issue of the sensibility of disability

rates in the population for cohort and period effects, and that one must consider the contextual perspective in disability models. They found, for example, that period changes in social class and health behavior affected improvement in the population. Similarly, Parker et al. (2005) suggested that the lack of change in ADL in their study could be due to the subjective nature of ADL and its vulnerability to changes in environment and expectations. However, in this study, two different samples were used, and data concerning ADL were collected at different times and, in two different municipalities. Still, ADL was strongly and significant related to the use of formal care and institutionalization in both samples, and it seems that ADL is a stable predictor of care patterns.

Another issue raised in measurement of ADL is the gender differences that are usually found. Romören and Blekesaune (2003) found that, similarly to the third study on H70, the probability for men to be institutionalized during old age was lower than for women and they suggest that it could be explained by the informal care given by their wife, as discussed, and also by the fact that men had shorter terms of disability before dying in comparison to women. This explanation is the most common used when discussing gender differences in ADL and the effect on patterns of care. Avlund (1997) offer another explanation, namely that gender differences found in ADL function could be a result of the questions asked. If the ADL measure used includes many questions concerning IADL, it might not give a fair picture of ADL problems due to health problems but rather ADL problems due to situational factors.

The large influence of ADL could therefore be considered as a sign of effective targeting by the formal care system, but there might also be gender and/or cultural effects, and/or time or period effects. Since both studies demonstrated a large effect from ADL, and they are performed at different time periods with different samples at different ages, the suggestions about effective targeting appear more likely. Nevertheless, the gender issue needs to be discussed. The ADL-measure used in NONA included ten items, of which six were categorized as personal ADL (bathing, getting dressed, going to the toilet, move from one position to another, continence and eating) that are considered not to be effected by gender, culture or interest. This is also how Avlund (1997) discussed PADL: in terms of tasks that all perform if they are able. On the other hand, the IADL items (cooking, cleaning, transportation, and shopping) used in NONA could be affected by gender. Among the elderly and oldest old, it is not uncommon to find men who not have performed any cooking or cleaning in their previous lives, and women who have not been driving. However, in the NONA study there were no gender differences in the total measure of ADL (including both IADL and PADL), and perhaps the fact that six of ten items are PADL

tasks explain the lack of gender difference. In the H70 study, ADL was measured with a scale that also mainly included PADL tasks, and even if there were gender differences in the patterns of institutionalization, it was probably not due mainly to the ADL measure. There were no gender differences in ADL at any age in the H70 study or the NONA study. The ADL function declined with age though, in both studies, with the most rapid decline in the H70 study occurring between the ages of 79 and 85 years.

Guided by the resource theoretical model, ADL is supposed to be an indication of lack of resources relative to demands from the environment, which in turn would affect the outcome in terms of use of care and/or institutionalization. Even though demands from the environment were not measured in this study, ADL provided a good measure of when the elderly individuals' resources failed to meet the demands of the environment. Perhaps ADL should be regarded as a mediator between resources and the environment. Femia et al. (2001) concluded that in a sample of oldest old Swedes, subjective health, depression and social integration mediated some of the influence of the functional impairment and limitations. In the first study, one of the aims was to determine whether ADL mediated any of the effect of resources on formal care. The results of two linear regression analyses indicated that, to some extent, ADL works as a mediator for the perceived resources in that sample of the oldest old. The results in the NONA study suggest that even though ADL has high impact on patterns of care, ADL interacted with other factors as well, in a complex structure.

Regarding patterns of informal care, the first study based on NONA demonstrated that the oldest old living in the community were more likely to receive informal care if they had only IADL problems, and were more likely to receive formal care if they had problems with PADL. These data confirm previous results showing that the oldest old get formal assistance when they have severe ADL problems. In addition, the attempt to find factors related to informal care demonstrated that subjective health and ADL were significant related to use of informal care only, and that objective health and ADL were related to use of informal and formal care combined.

It is surprising that social network factors did not turn out to affect the use of informal care. However, in NONA the source of informal assistance is not known, which suggests that spouses provide most informal care, and the informal care given would therefore not be affected by contacts with children. This contradicts other studies that have shown that children (daughters) seem to take a greater responsibility today (Johansson et al. 2003) but also that children tend to

assist more in older age groups (Hellström and Hallberg 2001). On the other hand they (op.cit) also concluded that it was among elderly couples that the informal care took place. Yet, because there is no information regarding the source of informal assistance, this dissertation cannot support either assertion. Further, it was only about one third of the NONA sample who were still married and possibly could have obtained informal assistance from their spouses. As discussed in the introduction the puzzling results concerning ADL and use of care could depend on the questions asked. In the NONA study the data on informal assistance is based on the ADL questions and who helped when they were not able to perform the tasks themselves: informal sources, formal source or combinations of both. It might be that the oldest old individuals received informal assistance for tasks other than those under study. The second study showed no increase in the use of informal care, only in the use of formal care. It is possible that the oldest old individuals have many chronic illnesses and disabilities that force the formal care system to take over.

#### **5.4. Strengths and limitations of the studies**

The strength of this thesis was the possibility to analyze relations among resources and care patterns in two different samples both cross-sectional and longitudinally, and with different inclusion-ages. The H70 study ranged over a 30-year period, with the possibility to analyze risk of institutionalization from the age of 70 to 100. The H70 study also enabled three different analyses of institutionalization, which should give an accurate image of the situation.

The strength of the NONA material is that it is a longitudinal study of a sample of the oldest old, with the age at baseline from 86 – 94, and at the final wave between 90 and 98 age years old. Due to the methodological problems that may appear when studying individuals in these advanced ages, the number of longitudinal studies in those ages are relatively rare.

Also the fourth study is to some extent unique since there are not many studies performed with that design, and/or with the aim to investigate the end-of-life care in the oldest old. In this study it was possible to analyze the last year of life of the oldest old based on proxy answers. Of course the resource theoretical model could not be fully applicable in those analyses, since the proxy interview precluded the possibility of assessing the perceived resources of the oldest old individuals. However, it was possible to relate the answers from the oldest old with those from

their relatives. Those analyses showed that in the preceding interviews, the elderly's subjective health ratings were more highly correlated with the proxies' health ratings than with their own objective health ratings. That is, the proxies' estimation of health seems to have been more sensitive to the elderly relatives' perception of health than to the number of diseases, medications, and visits to the hospital and general practitioner. Overall, the proxies' estimations corresponded quite well to how the elderly themselves had answered in the interviews. One can therefore assume that the proxies in this study were aware of the elderly individuals' situation and that the estimates reflected the actual situation.

The two materials gave a great possibility to perform several different analyses to investigate care patterns from the resource theoretical point of view.

There are limitations in the studies that need to be addressed. Firstly, conclusions drawn from the studies based on the NONA sample are hampered by the small sample size. As mentioned in the introduction, the population of the oldest old is unique and studies often include methodological problems, such as large non-response rates. In the NONA study, the participation rate reached only 56%. Because disease and disablement correlate highly with old age, a large non-response rate was expected in the NONA study, and proxies were used to substitute for those unable to answer for themselves. However, because one of the aims of this thesis was to find out how perceived resources are related to actual resources and how perceived resources affect patterns of care, it was not possible to use proxy answers. Therefore, the sample was reduced to 157 persons in the first wave, with increased attrition for each wave.

The sample size influences which analyses are possible and how many variables can be used. In the first study, descriptive analyses were performed most, but regression analyses were also performed. Because of the sample size, the indexes (actual and perceived health and social network) were used, and the effect from the single items could not be analyzed because it would have jeopardized the power of the analysis. The conditions were the same for the second study that only focused on health and ADL. It was possible to analyze social network factors longitudinally, as described in the second study; however, when using Cox regression to analyze survival the co-variables were restricted to health and ADL. The small sample size must be kept in mind when interpreting the results and one must be cautious about generalizing to the at-large population of the oldest old.

Another concern is that samples from both NONA and H70 must be considered local, limiting our ability to generalize the results. The sample in the NONA study is drawn from the municipality of Jönköping, a middle-sized municipality with both rural and non-rural areas, which should increase the possibility of a fair description of the oldest old that could be general to the Swedish population. The H70 study included respondents from Gothenburg, the second largest city in Sweden. Rinder et al. (1975) analyzed the sample and found the participants to be representative of the population as a whole in most aspects studied. However, they found a higher proportion of somatic care in the female response group as compared to the non-response group. When interpreting the results from the NONA and H70 studies, one must consider that the samples are drawn from two municipalities and that they are not necessarily representative of the Swedish populations as a whole.

Answers from individuals with severe cognitive problems have not been used. Elderly persons with cognitive problems or dementia are a special group that requires special treatment in special institutions for demented elderly. If the elderly with such problems had been included in this study, low cognitive function would probably have had great impact on institutionalization (e.g. Agüero-Torres et al. 2001) and patterns of care (e.g. Larsson and Thorslund 2002; Larsson et al. 2004). Yet, because the aim was to catch the perceived dimension of the respondents' health and social network, the subjects must be able to respond by themselves.

Also, nearly all measures (with the exception from objective health in H70) are self-reported which need to be noted as well. The significant correlations between the more objective resources and the perceived resources could to some extent depend on that fact. Perhaps interpersonal resources, like objective and subjective social networks, are not as sensitive measures of health as are individual resources. The measures of objective health are hampered with the same methodological difficulties discussed by Parker and Thorslund (2007): a mix of questions about symptoms and diseases. As in the NONA study, elderly individuals might have difficulty remembering all of their symptoms and diseases, and only the most obvious might be the ones to be reported. It is possible that the symptoms reported are more subjective than a diagnosed disease and might be over-reported. On the other hand, in the NONA study, perceived health was not as highly correlated to the objective measure as was perception of social network. If the diseases reflected other causes, such as dissatisfaction with the social network situation or loneliness, one could assume that it would also have been reflected in the perception of health. The converse is also possible. Additionally, symptoms might be underreported because the elderly consider them as "normal ageing". For the NONA study, visits to the hospital and general

practitioner were also included in the index of objective health, which might have contributed to the objectivity. Other studies have also found that even if the oldest old individuals report more diseases and symptoms they seem to manage to live independently (Parker et al. 2005; Spillman 2004; von Strauss et al. 2000), therefore, objective health would not affect use of care or institutionalization. The fact that these data came from self-reports must be considered when interpreting the results, this also applies when interpreting ADL result, which is also self-reported and not performance-based. The measurement method could account for the correlations between perceived resources and ADL.

## **5.5. Practical implications**

As shown in analysis of both NONA and H70 studies, ADL is the most important factor influencing formal care in the community and institutionalization. However, it is important to consider the gender effects when measuring ADL. The practical implication from these results is therefore that ADL measures must be constructed to fit both women and men, and possibly to fit individuals with different leisure time interests and individuals from different cultures. Although, because ADL also, to some extent, works as a mediator of perceived health and perceived social network, affecting patterns of care in the oldest old, it is also important to consider the perceived resources. Targeting individual and interpersonal resources when developing assistance programs for the oldest old would maybe enhance perceptions of health and social support which in turn might affect dependency and patterns of care.

Another practical issue to consider is the consequences of the increased need for social services and care among the oldest old, as suggested by Thorslund et al. (1991). According to existing knowledge families do contribute more to the care of the elderly (Hellström and Hallberg 2001; Johansson et al. 2003; Larsson 2006; National Board of Health and Welfare 2005a; Sundström et al. 2006). The results from the NONA study could, to some extent, confirm previous results. It appears as if informal caregivers provide assistance with IADL to a great extent, but on the other hand, when need increases, the formal care system takes over. Those results could suggest cooperation between the families and the formal care services. The great impact from ADL on both patterns of formal care in the community and institutionalization might also be an indicator of tougher decisions about priority, which also leads to an effective targeting based on needs.

Will there be a need to expand institutional care in Sweden due to an increasing number of the oldest old? The H70 study suggests that objective health (number of symptoms) and ADL are the most important factors influencing institutionalization. The NONA study demonstrates that both objective health (including number of diseases/symptoms) and ADL function decreased significantly over the four years studied. Previous research (Parker and Thorslund 2007) also demonstrated an increase of chronic diseases in the elderly population at the same time as the ADL function of the elderly population seems to be stable (Parker et al. 2005) or even improved (National Board of Health and Welfare 2005a). On the other hand, von Strauss et al. (2000) suggest that the absolute numbers of disabled older people will remain, due to the increase of the population of the oldest old.

In addition, the NONA study indicates that the perceived resources are of greater importance for care patterns in that group of the oldest old. Self-rated health and perceptions of the social network seem to be stable in advanced ages. ADL, on the other hand, is the strongest predictor for institutionalization in NONA as well. The results from the three studies do suggest somewhat different scenarios, and the trajectories of institutionalization are different depending on which age group is analyzed. The third study might be the most appropriate to describe risks of institutionalization due to the different analyses performed and considering the long (30 years) period that were studied. According to the results from the third study, the true extent of institutional care is greater than what could be assumed from cross-sectional studies, and perhaps there will be need for expansion of institutional care, or at least a more efficient use of it.

## **5.6. Conclusion**

According to the first cross-sectional study, perceived resources affect patterns of care to a higher extent than the more objective resources in this sample of the oldest old. Further, the type of ADL problems affect the type of care received: the oldest old living in the community and having IADL problems were more likely to receive informal assistance, but if they had PADL problems, they more often received formal care. ADL was strongly related to both use of care and institutionalization, indicating an effective targeting of the formal care system in Sweden.

There were further indicators of terminal decline in objective health and ADL but subjective health remained stable in the NONA study. However, survivors estimated their health as

significantly better at baseline, which could indicate an expression of decline in perceived health in relation to death even if the pattern of terminal decline was more apparent in objective health and ADL. The results also indicate that adaptive processes, concerning health, take action in advancing age. Furthermore, the decline in ADL function was highly correlated to the increase in use of formal care, and once the oldest old individual entered the formal care system they rarely got out.

The third study concluded that the proportion of elderly persons' institutionalization was significantly higher than that generally found in cross-sectional studies. Furthermore, in contradiction to the first study of NONA, the sociodemographic variables gender, marital status and SES, in addition to the more objective resources of having children living nearby and number of symptoms predicted institutionalization during a subsequent 30-year period. The gender differences that were found in the protection from institutionalization need to be further investigated and highlighted in future studies.

End-of-life care for the oldest old is challenged by the problems with progressive declines in ADL and health, as demonstrated in the second study, which make it hard to accommodate the oldest old who are dying in the palliative care system. There is also a need to increase the knowledge concerning the importance of supporting the social network for the elderly at elder care institutions, where most of the oldest old spent their last days.

Even if ADL is the most important factor affecting care patterns, whether informal, formal, or institutional, that is just the half-truth. This dissertation shows that the resources of the individual also play an important role, and for the oldest old, perhaps perception of resources is the most important factor. The third study also indicated marital status and gender have an additive rather than interacting effect on institutionalization.

Social network factors are of importance when it comes to institutionalization, and indirectly for patterns of formal care, since they are significantly related to ADL. There are further gender differences in the role of social network factors, and the formal old-age care system must pay greater attention to these differences as well. More importantly, all four studies substantiate the need for care staff to support and encourage the interpersonal resources and for decision-making staff to consider factors beyond ADL when developing strategies of care.

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